

**NURSES' ATTITUDES, COMPASSION SATISFACTION AND COMPASSION FATIGUE ASSOCIATED WITH  
THE PAIN MANAGEMENT OF PATIENTS WITH SICKLE CELL DISEASE CRISIS IN SAUDI ARABIA: A  
QUALITATIVE DESCRIPTIVE STUDY**

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## DECLARATION

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## ABSTRACT

**Background:** Sickle cell disease (SCD) is one of the chronic haematological disorders. It is common in African as well as in Indian- Arab originals. Saudi Arabia (SA) is one of the Arabian Gulf countries that has a high percentage of this disease especially in the Eastern province.

**Literature review:** Health care providers' attitudes vary between positive and negative towards sickle cell patients, especially in relation to pain and drug addiction. This variation depends on several factors such as: providers' experiences, number of treated patients and lack of knowledge about this condition. Registered nurses who work in critical services have moderate job satisfaction, and mild to moderate compassion fatigue. There was no study that examines the effect of treating patients in pain on nurses' level of compassion satisfaction and compassion fatigue. Although the percentage of sickle cell patients in SA is high, there are no studies that consider nurses' attitudes toward those patients.

**Methodology:** A descriptive qualitative design was used to explore nurses' experiences and attitudes towards patients with a painful crisis from SCD. Semi-structured, audio recorded interviews were conducted with registered nurses ( $n= 10$ ) working in the critical areas of Emergency Department, Inherited Blood Disorders Centre and Intensive Care Unit.

**Results:** Three themes were obtained from the data analysis. The participants found caring for sickle cell patients difficult and stressful. This care has an influence on their professional and personal life. The participants showed moderate to low compassionate fatigue and high to moderate compassion satisfaction while caring for sickle cell patients.

**Implications:** There is a need for further research, larger and replicated studies would provide a stronger basis for determining key aspects of this phenomena. Based on this study's findings education related to SCD and pain management to improve nurses' knowledge about the disease might support their capacity to care.

**Conclusion:** Nurses were affected by the experiences of caring for patients with sickle cell crises characterised by pain. The nurses' attitudes toward these patients varied. Sometimes their attitudes were positive and they were motivated to assist as fully as they could. At other times they experienced frustration and a range of barriers, which negatively affected their capacity and attitudes to care.

**Keywords:** Sickle Cell Disease, Nurses' Attitude, Compassion Satisfaction, Compassion Fatigue, Saudi Arabia.

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## LIST OF ABBREVIATIONS

ACS	Acute Chest Syndrome
BO	Burnout
CF	Compassion Fatigue
CS	Compassion Satisfaction
ED	Emergency Department
IBDC	Inherited Blood Disorders Centre
ICU	Intensive Care Unit
SCD	Sickle Cell Disease
STS	Secondary Traumatic Stress
UK	United Kingdom
USA	United States of America

## **CHAPTER ONE: INTRODUCTION**

This chapter is an opening window to the research that introduces the study interest, including the main objective of the study and the reasons for choosing this area to study. This is followed by an introduction to some basic facts about sickle cell disease (SCD) including its signs and symptoms, the common complications, vaso-occlusive crisis and pain. This study was conducted in Saudi Arabia so some brief facts about the country and population, and the distribution of SCD among the country are presented. Finally, a general view about compassion satisfaction and compassion fatigue in nursing is introduced.

### **The Aim of this Research**

The main objective of conducting this research was to explore nurses' experiences and attitudes toward patients with SCD who have painful crisis, in critical areas of a hospital setting. It aimed also to consider the effect of caring for patients during painful crises on registered nurses' levels of Compassion Satisfaction (CS) and Compassion Fatigue (CF).

### **My Interest in this Research**

I cared for patients with SCD for almost nine years in different hospital departments such as the Emergency Department, the Medical Ward and the Intensive Care Unit. I have seen patients with SCD suffering from pain even after receiving their analgesia dose. As a new staff nurse I had to consult my senior nurse and the physician before administering any medication. However there were delays in administering the analgesia and unprofessional judging about patients' pain appeared to be taken blindly. It was a stressful situation when seeing a patient in such pain and I could not help in relieving it which gave me the feeling that I was not doing any good for my patients. The hospital I used to work in has a high incidence of treating patients with SCD. In 2014, 73 SCD patients were admitted to the intensive care unit with a painful crisis.

### **Background**

This section is an introduction to the SCD, its definition, the global view about it, the signs and symptoms, painful crisis and complications in general. Then there is an introduction to Saudi Arabia followed by describing the epidemiology of the disease in Saudi Arabia.

## **Sickle Cell Disease (SCD)**

### **Definition**

SCD is a general name for different conditions based on the gene type presence such as: HbSS, HbSC disease, HbSB thalassemia, SO Arab, HbAS trait and SD Punjab (Lal, & Vichinsky, 2007; Rees, Williams, & Gladwin, 2010). It was discovered for the first time in 1910 by Dr James Herrick when he examined his first case and described the red blood cells as “The shape of the reds was very irregular, but what especially attracted attention was the large number of thin, elongated, sickle shaped and crescent-shaped forms” (Herrick, 2001, p. 181).

SCD is a term that has been used to describe several haematological conditions. It is one of the hereditary diseases that can be inherited from either one parent or both parents. When this gene is inherited from one parent the child will have HbAS ‘heterozygous’ and it is called a trait; if both parents carry the trait their children will have the disease and their HbSS ‘homozygote’ is what defines their condition. This is called sickle cell anaemia and it is the most severe type of sickle cell (Epstein & Bunn, 1997).

The Stedman’s medical dictionary for the health professions and nursing defines SCD as “a disorder resulting from abnormal sickled-shaped erythrocytes containing haemoglobin C and S that appears in response to a lowering of the partial pressure of oxygen” (2012, p.1428). It is a chronic condition that is characterized by painful crises. The acute painful vaso-occlusive crises episodes are the main cause of hospitalization for patients with SCD. Throughout this chapter sickle cell anaemia (HbSS) is the focus because it is the most common feature of SCD that has been studied widely among SCD types.

### **Global Epidemiology**

According to the World Health Organization, there are 300,000 babies born every year with one of the severe haematology disorders worldwide. The spread of these cases are mainly in low to moderate income countries (World Health Organization, 2011).

In the United States of America (USA), the affected populations are either African American or Hispanic. Among the African American births 1 out of 500 have SCD, while among Hispanic birth babies is 1 out of 36,000 (Centres for Disease Control and Prevention, 2011). There are over 89,000 individuals with sickle cell anaemia distributed variably in different states of the USA. The disease accounts for about 113,000 hospitalisations each year and health costs of \$ 488 million, according to one estimate (Brousseau,

Panepinto, Nimmer, & Hoffmann, 2010). While in the United Kingdom, sickle cell anaemia is associated with considerable mortality. About 3,000 babies are born annually in England carrying the sickle cell trait, and about 178 of these are affected by the disease (Hickman et al., 1999).

### **Pathophysiology of SCD**

The normal and healthy red blood cells (RBCs) are round in shape and have elasticity that allows their free movement through blood vessels either the larger ones or the micro blood capillaries in order to deliver oxygen and nutrients to all body organs. On the other hand, RBCs with HbSS haemoglobin, which represent SCD, RBCs change their shape to be sickled and lose their elasticity. They become rigid which results in losing the ability to pass through small capillaries and this lead to accumulation of sickled cells, they cluster and form polymers which prevent blood flow. At the same time, HbSS experiences polymerization and depolymerisation again and again which leads to damage of the haemoglobin and eventually to the RBCs (Lal & Vichinsky, 2007; Malowany & Butany, 2012). New RBCs are continuously manufactured in the bone marrow but in sickle cell anaemia the rate of destruction exceeds the rate of formation. Also the life span of sickled cells is short, around 10-20 days compared to the life span of a normal RBC, which is about 90-120 days (Malowany & Butany, 2012).

### **Signs and Symptoms**

Symptoms of SCD usually appear later in life and they vary tremendously from person to person in both their form and severity. Many individuals show mild symptoms, while others exhibit very severe symptoms that require treatment in hospital. The number of RBCs in the circulation is low, which results in the body not getting the necessary oxygen to maximize activity. That is why anaemia produces fatigue, which is one of the most common signs of sickle cell anaemia. Other symptoms of sickle cell anaemia include dizziness, headache, difficulty in breathing, cold feet and hands, pale skin and jaundice (Kohne, 2011). Sickle cell disease results in anaemia and crises that take many forms, which usually last for between five and seven days. There are different types of crisis such as: vaso-occlusive, which is the most common type, splenic sequestration, skull bone infarction, aplastic, haemolysis and bone pain crisis (Olabode & Shokunbi, 2006).

### **Painful Crisis**

Vaso-occlusive crisis results from the accumulation of sickled RBCs in either the macro vascular or the micro vascular circulation. It accounts for most of the mortality of people with sickle cell anaemia. The

clinical manifestations of a vaso-occlusive crisis include pain, stroke, pulmonary hypertension, priapism, and chronic renal disease. At present, there is no established therapy, either prophylactic or interventional, to deal with these problems. Some helpful therapies include hydroxyurea treatment, which lowers the risk of sickling, decreases adhesion of RBCs to the vascular endothelium and causes red cell hydration (an anti-sickling effect). Nitric oxide releasing drugs can be used to inhibit platelet adhesion but it is noteworthy that nitric oxide can have detrimental effects. Antioxidants, statins and L-arginine drugs may also prove helpful in this regard (Hebbel, Vercellotti, & Nath, 2009).

Pain is the significant mark in SCD. It is classified in to three types; acute, chronic and neuropathic pain. The acute episode of pain is sharp and hurting sensations that begins from infancy age and continue with the patients for their life long. The duration of such episodes vary from one patient to another or from episode to another for the same patient, which may take between hours to weeks before it subsides (Ballas, 2011; Ballas, Gupta, & Adams-Graves, 2012). Balls et al. (2012) added that pain is the commonest cause of hospitalization among patients with SCD.

According to Ballas et al. (2012) the painful crisis is continues sign and most patients regardless their age have continues pain between the two episodes of painful crises. This was concluded from measuring patients' pain scores during the first admission, during the discharge period and during the time of the next admission. Adult patients between the ages of 18 to 30 years are the patient group with the most frequent visits to the ED and the highest rate for hospitalization because of pain (Brousseau et al., 2010).

## **Complications**

The presence of both painful crisis and anaemia that are characterized by reduction in blood supply to body organs which results in several serious complications such as: acute chest syndrome, acute multi organ failure, infection or sepsis, stroke, chronic anaemia, pulmonary hypertension, pulmonary embolism, vision impairment, renal failure, leg ulcers, depression, obesity, damage to bones, gallstones, priapism and sudden death which mainly occur after hospitalization. These complications affect patients' quality of life physically and psychologically and lead to immature death (Ballas et al., 2012; Darbari et al., 2006; Musumadi, Westerdale, & Appleby, 2012).

Acute chest syndrome (ACS) is a significant cause of morbidity and mortality in children who have sickle cell anaemia. Regan, DeBaun and Frei-Jones (2011) presented that ACS accounts for one fourth of mortality related to sickle cell anaemia. Moreover, acute chest syndrome during the early stages of life has negative effects on lung function. According to Allareddy et al. (2014), Platt et al. (1994), and

Vichinsky et al. (1997) individuals who died as a result of acute chest syndrome first experienced pain due to vaso-occlusion and within 48 hours of the onset of symptoms died. There are limited therapies for preventing the development of ACS. The use of hydroxyurea reduces the risk of acute chest syndrome in patients who frequently experience these episodes. The prevalence of SCD in Saudi Arabia will be discussed in the following sections.

## **SCD In Saudi Arabia (SA)**

SCD is a worldwide common disease that is found in many countries such as USA, UK, Africa, India, Brazil, Italy, Greece and Middle East countries. Saudi Arabia is one of the countries that have a large percentage of patients with SCD (Lal & Vichinsky, 2007).

### **Overview about SA**

The Kingdom of Saudi Arabia is the largest country among the Arabian Gulf countries. It is located in the south- eastern part of the Asian continent. It occupies about 2,240,000 square kilometres of Arabian Peninsula (The World Fact Book, 2015). The official language is Arabic and a large percentage of people speak and understand English. There are about 29,897,000 inhabitants according to the latest population pyramids of the world (2015), ninety percent (90%) of them are Arabs and ten percent (10%) are Afro-Asians.

### **Epidemiology of SCD in SA**

In Saudi Arabia, SCD disease is found all over the country with two provinces having the largest percentage of the disease, the eastern and the south-western regions (El-Hazmi, & Warsy, 1999). Table 1.1 illustrates the distribution of sickle cell disease among Saudi Arabia containing the percentage of patients with (HbAS) who are known as trait and patients sickle cell anaemia (HbSS).

**Table 1.1 Distribution of SCD Among the Saudi Arabian Provinces**

Province	Percentage of HbAS	Percentage of HbSS	HbS frequency
Eastern	21.3%	3.8%	0.1446%
South- western	11.97%	1.67%	0.0765%
North- western	7.54%	0.88%	0.0465%
Northern	1.3%	0%	0.0065%
Central	0.8%	0.09%	0.005%

(Information summarised and retrieved from El-Hazmi, & Warsy, 1999)

In 2008, Al-Qureshi, Al-Mouzan, Al-Herbish, Al-Salloum and Al-Omar found that the prevalence of SCD in SA is 24 cases per 10,000. The eastern region represented the highest prevalence of 145 cases per 10,000 while in the southern region has a prevalence of 24 cases per 10,000. In addition, between two and twenty seven percent of the population are thought to have the sickle-cell trait and a further three percent sickle cell anaemia (El-Hazmi, Al-Hazmi, & Warsy, 2011). Recently, the Ministry of Health in SA posted the percentage of population who have sickle cell anaemia, the most severe type of SCD, has reached 145,750 cases (Arab News, 2015).

The chosen hospital for data collection, in the current study, is one of the central hospitals in the eastern provinces with a total capacity of 365 beds. Patients with SCD frequently visit the hospital. The ED and the IBDC are the first place where they seek their care. According to the statistic department in the hospital for the period between the 1<sup>st</sup> of July 2014 and 31<sup>st</sup> of July 2015, the total number of SCD patients who visited the hospital complaining of painful crisis were 1,831 patients with a total number of 13,706 visits within the ED. In addition, a total of 1,360 patients were registered in the IBDC with a total of 12,286 visits during the same period. On the other hand, a statistical report from the ICU department about number of patients being admitted to the ICU between the 1<sup>st</sup> of January 2014 to 31<sup>st</sup> of December 2014 with a total of 73 cases range from one to five admissions each week. This requires knowledgeable and skilful health personnel to assess and manage those patients effectively.

Additionally, there were 470 deaths among sickle cell patients during painful crises between July 2013 and July 2014 out of 8,833 ED registrations in Qatif area. This is based on a local newspaper that

examined this issue from patients' perspectives and demands as well as from medical team point of view (Al-Hayek, 2014).

There are two main departments, the ED and the IBDC, which provide the initial emergency management for those patients. The ED is a general department which receives different cases from medical, surgical, paediatric and obstetric for all ages. In relation to SCD, ED provides care for adult female, pregnant woman and paediatrics at all time when they seek care for their symptoms. There are eight female examination rooms for all conditions and another eight beds for SCD patients as observation rooms. The IBDC is the sickle cell centre within the hospital that provides care and management for male patients only in mild to moderate symptoms. It is composed of six beds as emergency care and 20 beds for observation when it is required. For adult patients who complain of severe symptoms such as, shortness of breath or the patient presents with a life-threatening condition they are treated in the resuscitation room in the ED, before being admitted to the hospital either to the medical ward or ICU.

The general ICU accepts medical, surgical and gynaecology cases when care is required. It is fully equipped with mechanical ventilators, suctioning and the intensive management for different cases. SCD patients with painful crisis who present with complications such as: ACS, difficulty of breathing, severe anaemia, post-partum with eclampsia complications and pain are commonly admitted patients to the unit.

### **SCD and Nurses' Compassion Satisfaction (CS) and Compassion Fatigue (CF)**

Patients with such a chronic condition who suffer from recurrent episodes of pain and frequent hospitalisation may affect their physical, social and psychological functions which could influence their quality of life status (QOL). QOL is a difficult concept to be defined. In nursing, it is defined as an impalpable concept which involves the physical, social, psychological, economic and environmental wellbeing. It is mainly a subjective feeling that can be explained by the person himself but it can also be an objective assessment from other individuals as described in Futton, Miller and Otte's (2012) review on QOL concept in nursing.

Additionally, Felce and Perry (1995) formulated a model of QOL that is based on three parts including physical, social, mental and emotional wellbeing. The second phase is the individual satisfaction for being well and its importance for an individual to be well and healthy. Mann-Jiles and Morris (2009) surveyed 62 adult patients with SCD who reported their QOL score range from 57 to 112. Their QOL

score represented that most patients with SCD have low QOL, and the main focus of the patients are on being physically disabled and on not having a job.

The disease process does not affect patients only; it has an effect on patients' families and health care providers. Since nurses spend more time with their patients compared to other health care professionals, they may be influenced by the patient's condition and the surrounding environment could also affect nurses' QOL and professional judgment. Nurses sometimes feel disappointed when their patients are not getting better or if their conditions become worse. These feelings may develop negative feelings about their work and may affect it negatively (Todaro-Franceschi, 2013).

Compassion satisfaction (CS) and compassion fatigue (CF) are the main elements in evaluating professional quality of life. CS is the positive feeling that a worker has while performing his/her required job, happiness, and the ability to continue doing same task (Stamm, 2010). CS among 450 nurses working in acute areas was studied, 28.7% were satisfied (Burston & Stichler, 2010). CF is the negative feeling which is characterized by fear in association to work, and feeling crushed or defeated. There are two subscales under CF which are burnout (BO) and secondary traumatic stress (STS) (Stamm, 2010).

## **Research Approach**

A descriptive qualitative research informed this study to describe nurses' attitude, nurses' CS and CF while caring for patients with SCD during painful crisis. Ten registered nurses in Saudi Arabia, who work in the three critical areas for treating those patients, were interviewed. Three themes had been identified after analysing the collected data. These were the nurses' experiences of caring for patients with pain associated with SCD, the participants' attitude towards a patient with SCD during painful crisis and participants' CS and CF associated with managing patients with SCD crisis. These are reported in more depth later in the thesis.

## **The Contribution and Significance of this Research**

This is the first study in Saudi Arabia that concerns nurses' attitude towards patients with SCD during painful crisis. This subject had not been studied widely; there were few studies that examine nurses' attitude toward patients with SCD. The importance of raising this issue was to explore registered nurses' views about those patients and the effect of their view on the pain management process. In addition, it is the first study that examined the effect of caring for patients with SCD during painful crisis on nurses' level of CS and CF in critical areas.

## **Outline of the Thesis**

This thesis is presented in five chapters. In this first chapter an introduction to the research and the relevant background was provided. The second chapter presents formulating the research question, the search strategy throughout several databases for the previous literature in relation to the topic and the process of critiquing and synthesising the results from the literature which helped in identifying the gap in the research and the need to conduct this study. The chosen research design and methodology is presented in the third chapter. The principles of theoretical and conceptual framework, site accessing, sampling process, recruitments participants, the data collection process and guides, the data analysis, trustworthiness and maintain rigor process, and the ethical consecrations as well as the process of obtaining the ethical approval are presented. The fourth chapter presents the results under the three themes obtained through the content analysis. The fifth and the final chapter follows, this contains the discussion drawing the previous four chapters together in relation to highlighting the new findings, connecting with the current literature when applicable, providing some possible implications and limitations to the current study.

## **CHAPTER TWO: LITERATURE REVIEW**

This chapter introduces the search strategy that was followed to identify previous studies that examined pain management for patients with SCD, health care workers' attitude toward those patients when seeking ED care, IBDC care or when being admitted to the ICU, the identified barriers to effective pain management for those patients, and ED, IBDC or ICU nurses' level of compassion satisfaction, compassion fatigue, burnout and secondary traumatic stress. All studies that are included in this chapter were presented in detail in relation to the key words used, the inclusion and exclusion criteria, the search process, the information extraction and the synthesis of the extracted results in a meaningful manner.

### **Search Strategy**

In this section the search strategy that was undertaken to identify papers relevant to the literature review is described. The section reports on the databases and the search terms that were used.

An intensive search through four databases was conducted to find all published studies, systematic reviews and dissertations relating to nurses' attitudes, compassion satisfaction and compassion fatigue associated with the pain management of patients with SCD. The search was conducted by using: 'nurses' attitude' term there was only one study relatively to nurses and other studies were about 'health care providers' generally, so I changed the search term to attitude of health personnel. The initial terms that were used for the search were 'sickle cell disease', 'pain management', 'attitude of health personnel', 'emergency department', 'inherited blood disorders centre', and intensive care unit\*'. The search was conducted in the Cumulative Index of Nursing and Allied Health Literature, Pub Med, SCOPUS and Ovid MEDLINE. The search process in each database involved two phases.

The first phase combined three Mesh terms, which are 'pain management' AND 'sickle cell disease' AND 'attitude of health personnel'; the result from each database varied from zero to 12 articles. (The results are presented in Appendix 1a). The second phase aimed to identify previous studies that focused on 'compassion satisfaction', 'compassion fatigue', 'burnout', 'secondary traumatic stress', 'ED', 'IBDC' and 'ICU'. The search process was undertaken in two different ways. The initial search involved separating the search process by combining 'CS' OR 'CF' OR 'BO' OR 'STS' AND ['ICU' or 'IBDC' or 'ED'], and this approach resulted in 47 articles. These results are presented in Appendix 1b. A separate search through Cochrane library was conducted with the use of the first search keywords, and this approach resulted in

four systematic reviews in relation to pain management for patients with SCD during a painful crisis (Anie & Green, 2015; Marti-Carvajal, Pena-Marti, Comunian-Carrasco & Marti-Pena, 2012; Okomo & Meremikwu, 2015).

Okomo and Meremikwu's (2015) study is about fluid replacement therapy and its effect for painful episodes; this study was excluded due to the lack of evidence to build the systematic review and extract the evidence. Marti-Carvajal et al.'s (2012) research is specifically targeting pregnant women during painful crisis and the management protocol hence it was excluded from the literature review. Detailed tables about the search strategies and formulation of PICO question for the current research can be found in Appendix 1c. The searching process was first limited to the years from 2000 till 2015 as time was not considered as an important factor as gaining a larger selection of papers.

## **Research Critique Procedures**

In this section the details of process of selecting research papers for inclusion in the literature review are presented. This description includes information about the inclusion and the exclusion criteria for selecting research papers, evaluating the quality of each paper and the tools that were used for achieving the required quality of the literature, identifying the relevant results and synthesising them to formulate the final result.

### **Methods: Selecting Papers for Exclusion and Inclusion**

All studies that explore nurses' experiences of caring for patients with SCD during a painful crisis, studies that explain healthcare providers' attitude towards these patients as they seek care in either the ED, IBDC or ICU and those studies that focus on nurses' compassion satisfaction (CS), compassion fatigue (CF), burnout (BO) or secondary traumatic stress (STS) related to causes, symptoms and coping strategies were searched. Papers that specifically included adult patients with SCD children and adolescents were excluded because of the difference in the pain assessment tools they used and the current study focused on adult patients only.

The researchers should have used pain management and SCD, ED, IBDC, ICU, CS, CF, BO and STS indicators in their discussion. Systematic reviews, literature reviews and original articles were included. Peer-reviewed articles published in academic journals from 2000 until 2015 were considered. Papers that have published abstracts are written in English language, have their full text available and concerns adult patients with SCD were included. All the studies that had been found in relation to the topic were

included in the literature review after meeting the inclusion criteria. Literature review papers were also included due to the insufficient studies that had been conducted in this search area.

**Methods: Appraising the Quality of Papers**

After gathering all the possible articles that will answer the research question, an inclusion assessment criterion was created (See Table 2.1). After the initial scan of potential papers to be included a detailed and critical assessment for each paper has been conducted. A critical appraisal assessment checklist was used as guidance in assessing the potential studies to be included in the review, besides evaluating each author by identifying his/her H index scale beside the speciality and other research that has been conducted by the same author if in the same field of the research or not. Journal quartile has been identified through the impact factor of the journal and its quality. For some papers the impact factor was not available so the scientific journal ranking (SJR), impact per publication (IPP) and source normalized impact per paper (SNIP) were presented. Papers that have been published in Q 1 and Q2 journals were included and some studies with Q 3 were included when they were strongly relevant to the topic and the critique assessment for the research had shown its strength.

**Table 2.1 The Inclusion Assessment - Criteria Form**

Criteria	Yes	No	Not sure
Population Paper about SCD, pain management, health providers’ attitude, CS, CF, BO, STS Adult patients management			
Pain management in either ED, IBDC or ICU			
Outcomes HCPs’ attitude while caring for patients with SCD, Barriers to effective pain management ED nurses’ CS, CF, BO and STS IBDC nurses’ CS, CF, BO and STS ICU nurses’ CS, CF, BO and STS			
Time-frame Published between 2000-2015			
Author standing Area experience Publication track			
Journal quality Peer-reviewed			

Impact factor/ JCR and or Journal Ranking			
Context specific information Country/ state- research setting			
Type of research design Name:			
Acceptance for inclusion			

In addition to the general quality assessment of each article, Critical Appraisal Skills Program (CASP) (<http://www.casp-uk.net/#!/checklists/cb36>) assessment tools were used to measure the quality of each study deeper. The chosen tool was based on the used methodology, three checklists were used: the systematic review, the qualitative checklist and the cohort study check list.

### **Methods: Grouping Results and Extracting Data**

The data was extracted from the results section of each paper found relevant to the study. The results were related to pain management protocols in either ED, IBDC or ICU, health care providers' attitudes while caring for those patients during painful crises, some barriers that may affect pain management efficacy, and ED, IBDC and ICU nurse levels of CS, CF, BO, and STS. For comparison, related results were highlighted in each paper with different colours, according to the similarity. The first reviewer extracted the relevant data, which was checked by the second reviewer in order to evaluate its accuracy and relevance. General information about each study paper was extracted in relation to the setting, participants' characteristics, and the country where the study took place (see Appendices 2 & 3).

### **Overall Results and PRISMA Flow Chart**

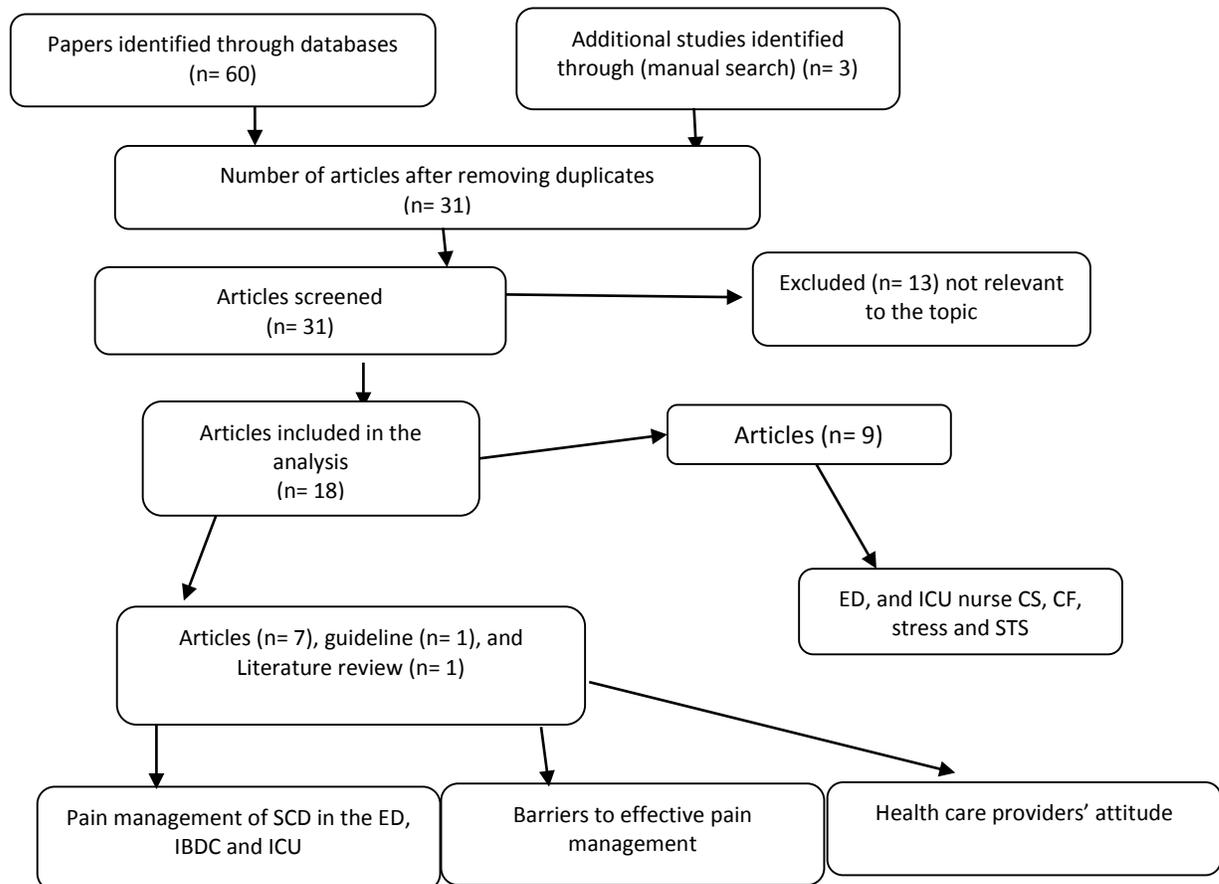
This section describes the flow of research assessment based on the relevancy to the topic, building up the PRISMA chart as a quick reference for the studies has been used and the extracted result. This section also includes the process of clustering the result and formulating the themes that are relevant to the founded result.

### **PRISMA Style Flow Chart**

In the first search, a total of 13 articles were located that are concerned mainly with pain management in SCD and healthcare providers' attitude to patients and 47 studies that are concerned with ED, IBDC or ICU, nurses' CS, CF, BO, and/or STS. Three studies were found through a manual search. Thus, a total of 60 papers that are relevant to the research question were located. Of these, 29 studies that were

duplicated in more than one database were excluded. The abstract for the remaining 31 studies were read. Thirteen research papers were excluded due to the irrelevancy to the research topic. Therefore, the results reported here and included in the critical appraisal indexes had been extracted from 17 articles and one guideline. The result concerning pain management and health providers' attitude towards patients with SCD were retrieved from eight studies and one guideline, and nine articles were used to formulate the presented result related to ED, IBDC or ICU nurses CS, CF, BO and STS. One guideline related to the pain management protocol for patients with SCD was included in the review to formulate standing phase for the proper management flow for such patients. The following PRISMA chart summarizes the searching process till formulating the last phase of extracting the presented results that had been found in the literature. No studies were located regarding IBDC for pain, for nurses' attitudes and for nurses CS and CF.

**Figure 2.1 A PRISMA Style Flow Chart for Retrieved, Excluded, and Included Papers**



Adapted from: the style of the PRISMA chart available on [www.prisma-statement.org](http://www.prisma-statement.org)

## **Classification of Results**

The extracted data has been presented under four main themes which are: Pain management of SCD in the ED, IBDC and ICU; health care providers' attitude; barriers to effective pain management; and ED, IBDC and ICU nurses CS, BO and STS. Some themes were presented with sub-themes when it is applicable to present the detailed information. The included research for health care providers' attitude towards patients with SCD were seven articles: three cross-sectional studies (Glassberg et al., 2013; Labbe, Herbert, & Haynes, 2005; Pack-Mabien, Labbe, Herbert, & Haynes, 2001) one qualitative study (Booker, Blethyn, Wright, & Greenfield, 2006), a systematic review (Haywood et al., 2009), a cohort study (Ratanawongsa et al., 2009), one prospective longitudinal cohort study (Porter, Feinglass, Artz, Hafner, & Tanabe, 2012) and one retrospective historical cohorts research (Tanabe et al., 2007). One literature review (Wright, & Adeosun, 2009) and one pain management guide line for painful crisis in SCD (National Heart, Lung and Blood institute, 2014). These studies were originated from either United States of America (USA) or United Kingdom (UK). While a total of nine articles have been included in relation to CS, CF and BO among ICU, IBDC or ED nurses eight of them are cross-sectional (Adriaenssens, Gucht, Doef, & Maes, 2011; Healy, & Tyrrell, 2011; Hunsaker, Chen, Maughan, & Heaston, 2015; Karanikola, Papathanassoglou, & Mpouzika, 2012; Laposa, Alden, & Fullerton, 2003; Ozden, Karagozoglu, & Yildirim, 2002; Shoorideh, Ashktorab, Yaghmaei, & Majd, 2015; Young, Derr, Cicchillo, & Bressler, 2011) and one systematic review (Beck, 2011).

### **Pain Management of SCD in the ED**

Three studies that concern pain management in the ED were found and reviewed (Glassberg et al., 2013; Haywood et al., 2009; Tanabe et al., 2007). Each study involved a different research method. The first is cross-sectional, the second is a systematic review and the third is a retrospective study. All of the studies were conducted in the United States of America. Glassberg et al. (2013) targeted health care providers working in the ED, including physicians, nurses, medical students and residents. Tanabe et al. (2007) included adult patients with SCD during painful episodes, while Haywood et al. (2009) combined two target groups (patients and health care providers).

In the ED, pain management for SCD patients starts in the triage room. According to the American National Heart, Lung and Blood Institute [NHLBI] (2014) patients with SCD during painful episodes, with scores of seven or more out of 10, should be categorized as second-priority for treatment. This contrasts with what Tanabe et al. (2007) found in their retrospective study of 529 visits of patients with SCD with

pain over 12 months. Most of the patients presented to the ED with pain score of seven or more but were categorized between second- and fifth-priority, which resulted in delayed pain treatment and increased patient suffering. The reason behind these variations was not clear. It might have resulted from triage nurses categorising their patients based on their judgment rather than the actual patient presentation, or could be because some nurses were not familiar with the coding codes protocol, particularly for patients with SCD. All of the information in this study was also taken from patients' medical records, which may not contain all of the details required for a full understanding of the situations involved.

The subjective and objective assessment of pain must be performed prior to administering treatment. If pain is mild to moderate, non-steroidal anti-inflammatory drugs (NSAIDs) can be prescribed if they are not contraindicated based on patients' past medication and allergic histories. In cases of severe pain, opioids must be administered. The recommended analgesia during acute painful crisis is either morphine or hydromorphone, and the dose should be given either intravenously or subcutaneously, while intramuscular and oral routes are not recommended. The initial dose of analgesia should be administered within 30 minutes of triage assessment, or at 60 minutes after ED registration (The American National Heart, Lung and Blood institute, 2014). Research has shown that most of the patients with SCD received the recommended dose of either morphine or hydromorphone (Tanabe et al., 2007). In addition, Glassberg et al. (2013) reported that the majority of HCPs follow the recommendations from the pain management protocols in relation to describing pain analgesia. The routes of administration vary between intravenous (IV), subcutaneous (SQ), intramuscular (IM) and oral (Tanabe et al., 2007; Glassberg et al., 2013). Although most patients receive either IV or SQ analgesia, some patients get IM and oral medication, which are not recommended. There is no explanation for the use of such routes of administration, although they might be the preferred routes of patients.

Over all the studies which examined the timing of initial management within the ED, some factors had been identified that may influence this delay for instance, patients' gender. For example, female patients were found to wait longer than males by 21 minutes. The triage category was found to be another factor, and the mean wait time difference between patients in category 1 or 2 and category 3, 4 or 5 was 45 minutes. Intravenous availability was also found to be a delay factor, and patients without IV access waited longer than those who had IV access, by a mean of 24 minutes (Tanabe et al., 2007). There is no explanation for this delay, although female patients may have had to wait longer because

they visited the ED more frequently to obtain treatment. In addition, IV availability should not be a reason for delaying drug administration, since there are different routes that can be used.

Glassberg et al. (2013) point out the prevalence of health care providers' ordering of patient-controlled analgesia (PCA) for patients with severe pain. Providers treating paediatric patients are six times more likely to order PCA than those caring for adult patients. This result does not match with the recommended treatment for SCD in the American guidelines, which states that adult patients need to get PCA when necessary (NHLBI, 2014). This result may be explained by providers' behaviours toward their patients. There is typically a fear of addiction and drug abuse when adult patients seek ED care (Glassberg et al., 2013).

The pain management for patients with SCD depends on both the subjectivity of patient's complaint and the objectivity of providers' assessment. Providers differ in their assessment and categorizing for patients to be treated although patients were presented to the ED with the same complaints and reported similar pain score. The general outcome from those researches that HCPs try to maintain the required pain management protocols for all patients but there were some factors that may interfere with these decisions.

### **Health Care Providers' Attitudes (HCPS)**

Health care providers' attitudes to caring for patients with SCD have not been investigated widely, although some studies in the US and the UK have focused on this issue. There was only one study from the search that addressed nurses' attitude (Pack-Mabien, Labbe, Herbert, & Haynes, 2001). A total of 77 nurses working in a teaching hospital in USA completed the questionnaire to evaluate their attitude and its influence on the provided care for patients with SCD during painful episodes. Sixty three percent of the participants said that patients with SCD are drug addicted, 97% of these nurses also believed that even if these patients are addicted, the patients do have actual and painful SCD episodes. Although nurses thought that patients with SCD are addicted, they did not consider it as primary concern while managing their pain. The nurses' age, experience and educational level were found to influence nurses' attitudes when caring for patients with SCD. Nurses, who are older in age, have more experience and who have higher degree in nursing tended not to worry about drug addiction when they were caring for patients with SCD.

Ratanawongsa et al. (2009) examined patients treated for pain secondary to SCD and their health care providers to validate an attitude scale on HCPs attitudes' towards patients with SCD. One of

Ratanawongsa et al.'s study results was that in-hospital providers of care were more positive to their patients than ED providers were. Patients' educational and economic status correlated with healthcare providers' attitude. In particular, patients with high education, who are employed and have a stable income received more positive attitude from healthcare providers than those patients with a low education level or who are jobless. Certain factors were found to influence providers' negative attitude, and these were patients' frequent hospitalisation, patients' previous bad behaviour toward HCPs and patients' presentation with certain conditions, such as acute chest syndrome and vascular necrosis.

Nurses had more positive attitude towards their patients than other healthcare providers had, but patients' perceptions indicate that their nurses treated them with mistrust, suspicion and neglect during their painful episodes, as indicated in the systematic review of Haywood et al. (2009) and Booker, et al. (2006). Overall, these studies highlighted an important aspect that needs further investigation. Why do ED providers have a negative attitude towards their patients? In what way do nurses show their positive attitude? Do these findings suggest the poor communication between patients and HCPs? In contrast, Porter, et al. (2012) reported patients' perceptions on ED management; particularly, patients expressed that they were treated with respect and trust by their health care providers, especially by ED physicians.

Glassberg et al. (2013) conducted a cross-sectional study involving 671 healthcare workers, including physicians, nurses, medical students and other health workers, in the ED. Their study involved some factors that may affect healthcare providers' attitude towards patients with SCD, such as patients' age, number of patients treated per week and providers' ethnicity. The attitudes of healthcare providers vary between positive and negative, and adult patients' providers act negatively towards their patients compared with paediatric providers. Treating more patients with SCD was associated with providers' negative attitude, and this result might be attributed to the frequent seeing or hearing of the same complaints from patients. Seeing more patients with the same condition is supposed to open up providers' minds about the disease they are handling and make them learn more about it, so that they can control patients' symptoms efficiently and provide maximum care.

This study shows also the providers' ethnicity has an impact on their behaviour while caring for SCD pain. Black originated providers were more positive towards their patients compared to the white ones, but the number that has been included in the study in relation to ethnicity is insufficient. The white providers were 73.5% of total participants while the black providers represented only 5.9% of the participants. On the other hand, it may indicate ethnicity has an influence on providers' attitude since

these black providers are more exposed to the disease through contacting and living with those patients or having a family member who have the disease.

The commonly noticed behaviour from care providers towards patients with SCD was that patients were not being believed or they had been mistrusted when they report their pain. This resulted in delaying patients' care and patients may not ask for ED services when they are in pain which may result in increasing the mortality and morbidity rate among those patients (Booker et al., 2006; Haywood et al., 2009; Tanabe et al., 2007; Wright & Adeosun, 2009).

## **Barriers to Effective Pain Management**

Two main factors had been found as barriers for effective pain management in patients with SCD. These factors are: providers' knowledge about the disease and its management and providers' negative attitude toward those patients.

### **Providers' Knowledge**

One of the most highlighted barriers in pain management is providers' lack of knowledge about SCD itself, pain assessment process, and lack of experience with SCD patients (Haywood et al., 2009; Wright, & Adeosun, 2009). The aspect of lack of knowledge has arisen from patients' perceptions as well as from providers' one. Patients emphasize that providers have insufficient knowledge about the disease and its management while providers agreed they lack experience in caring for patients with SCD (Haywood et al., 2009; Booker et al., 2006). Booker et al. (2001) also highlighted nurses' lack of knowledge as a barrier to effective pain management beside other factors including: viewing patients as drug seekers, hesitance either from health care providers or patients (physicians would not prescribe analgesia, nurses would not administer the medicine, and patients some time refuse to have their pain relieving doses of medication), law and regulations related to prescribing opioids as well as the limited opioids available for treating pain.

### **Providers' Negative Attitudes**

The negative attitude that patients face from their providers when visiting ED for care is a major barrier for managing their pain. Negative providers' attitude, as discussed above, prevents patients from going to the ED when having pain or patients would delay their visit till their pain is exceeded their tolerance. Providers with a negative attitude may delay administering analgesia for their patients which put their

patients in high risk for developing other severe conditions which might be life-threatening ones (Haywood et al., 2009; Wright, & Adeosun, 2009; Glassberg et al., 2013).

## **ED, IBDC and ICU Nurses CS, BO and STS**

ED, IBDC and ICU are acute care settings and nurses have similar roles and responsibilities as well quite similar workload and all departments treat patients in their most critical conditions. In the next sections a description of the literature review findings regarding nurses' compassion satisfaction and compassion fatigue are discussed. Four studies that focused on ICU nurses CS and CF were identified. Five studies related to ED were identified, and as previously stated no studies related to IBDC were identified. In the following sections literature reviews in relation to each of the contexts are presented.

### **ED Nurses' CS, BO, Stress and STS**

Five studies had been found that examined nurses' stress and identify stressors among ED personnel. They were conducted in various settings such as USA, Canada, Belgium and Ireland.

#### **Stress Among ED Nurses**

ED is one of the stressful departments in a hospital setting which may affect health care providers physically and psychologically. Healy and Tyrrell (2011) found that ED personnel often face stressful situations while performing their duties. Examples of the factors that influence stress in the ED are the work environment, violence against staff, witnessing the death or resuscitation of a child or young adult, and caring for patients in critical conditions. The most reported factor was the work environment, which is often described as a lack of support from managers. This is consistent with the findings of Laposa, Alden, and Fullerton (2003) who examined the relationship between work place stress and the severity of posttraumatic disorder (PTSD) among ED personnel. They found that interpersonal conflict among ED personnel was the most notable stressor in the work environment that increased the severity of PTSD symptoms among ED staff. Conflicts between staff affect the professional work and judgments of staff, which may result in unsafe environments for treating patients.

Several factors affect the degree of stress suffered by health-care workers. Practitioners' age, the length of their professional lives, and their experience in the ED were found to be associated with the degree of stress. For example, in treating critical-care conditions, young practitioners felt more stress than the older ones (Healy & Tyrrell, 2011). Older staff's greater experience in treating patients in critical conditions builds their confidence and their ability to handle such situations, as opposed to new staff,

which may face such cases for the first time and may not receive the required help or assistance that they need from senior staff. This report did not involve other stressors and their relation to age, professional experience, and ED experience. ED workers showed moderate-severity PTSD symptoms. Laposa et al. (2003) detected a significant correlation between interpersonal conflict among ED personnel avoidance and arousal.

Beck (2011) carried out a literature search of secondary traumatic stress (STS) among nurses. Seven studies examined STS with ED, oncology, children's, and hospice nurses. The majority of the participants were female nurses. Overall, STS symptoms among nurses were moderate to high. Among ED nurses, approximately one third of participating nurses had a high level of STS, which was characterized by difficulty sleeping, getting annoyed easily, and thinking about patients' conditions. The samples in all the studies were small, and different scales were used to measure the same outcome, which makes it difficult to generalize or to compare outcomes. There was only one study conducted on ED nurses.

### **CS and Job Satisfaction Among ED Nurses**

ED nurses as shown above face stressors when caring for their patient, on the other hand some ED staff show high job satisfaction level when they have been asked to evaluate their satisfaction and fatigue levels. Adriaenssens, Gucht, Doef, and Maes (2011) conducted a cross-sectional research among 15 EDs in Belgium. ED nurses showed more satisfaction when working in different shifts, having more authority while caring for their patients, when their work being appreciated and having support from their supervisors. This satisfaction may be explained by their level of being involved in the work environment which gave them the sense of belonging to the department and being able to perform the required tasks with confidence. Rewarding was one of the variables that had significant correlation with job satisfaction, turnover intention, fatigue and work engagement. ED nurses wanted to be appreciated and their work to be valued to reach their satisfaction level and decrease the negative impression associated with the intention to leave their work. In addition, age and years of experience were found to be associated positively with both CS and BO.

In relation to age as a variable, young nurses with little experience tend to show less CS and more BO scores compared to older and expert nurses. This result had been supported by Hunsaker, Chen, Maughan, and Heaston's (2015) research that concerned CS, CF and BO among ED nurses in the USA. The common factor between these two studies is working in the ED from totally different countries and showing these similar results might be an indicator for a global standardised strategy to improve the

working environment factors and further studies about nurses reasons for leaving their work in order to build a healthy and satisfied personnel which might affect positively patients out comes and the care being delivered to these patients.

### **ICU Nurses CS, BO and STS**

Of the four ICU studies identified, three of them studied both concepts (Ozden, Karagozolu, & Yildirim, 2002; Karanikola, Papathanassoglou, & Mpouzika, 2012; Young, Derr, Cicchillo, & Bressler, 2011), and one study mainly was about BO (Shoorideh, Ashktorab, Yaghmaei, & Majd, 2015).

### **Job Satisfaction Among ICU Nurses**

Although each study used a different scale and was conducted in a different setting (USA, Greek, and Turkey), nurses working in the ICU were mostly found to have mild to moderate job satisfaction (Karanikola et al., 2012; Ozden et al., 2002; Young et al., 2011).

Ozden et al. (2002) distributed two sets of questionnaires to measure nurses' job satisfaction and BO among ICU nurses in three different teaching hospitals in Turkey. Nurses were moderately satisfied. These authors measured the correlation between job satisfaction and BO measures, and this showed job satisfaction to correlate negatively with depersonalization (DPS) and emotional exhaustion (EE) but positively with personal accomplishment. When a nurse had a high score in job satisfaction, therefore, she typically had a low score in both DPS and EE, while nurses with low scores in job satisfaction also tended to have low scores in personal accomplishment.

In a USA study, Young et al. (2011) evaluated nurses' CS, CF and STS by ProQOL 5 survey comparing ICU nurses and intermediate medical unit nurses. Although both departments' nurses show moderate CS, the ICU nurses presented lower satisfaction ratings. This might be due to the workload, type of patients, nurses' role differences, or the degree of cooperation between nurses while performing their tasks. The number of ICU participants was double that of the participants from the intermediate unit; it might be that only those who were satisfied from the intermediate unit participated. The patient death rate was higher in the ICU, which might have affected nurses' CS.

Karanikola et al. (2012) conducted their study among ICU nurses in both public and private hospitals. They found that nurses had moderate job satisfaction generally, but nurses working in the private sector showed a higher level of satisfaction than those working in the public sector. An interesting finding was that nurses showed less satisfaction when they had to work more weekends. There was no distinction

between the two sectors in relation to workload, nurses' authority in decision making, or nurses' benefits, so these probably did not influence the levels of satisfaction.

The studies were conducted in different countries and different settings but the result was similar. Registered nurses working in the ICU showed moderate job satisfaction in general. There were some factors that might influence their satisfaction such as patient's condition, nurse's responsibilities and working duties. After measuring the positive side of being a nurse in the critical area, it is more convenience to evaluate nurses' BO level with in the ICU.

### **Burnout Among ICU Nurses**

BO among ICU nurses was mostly in the average to high level (Karaniola et al., 2012; Ozden et al., 2002; Shoorideh, Ashktorab, Yaghmaei, & Majd, 2015; Young et al., 2011). Although these studies were conducted in different countries and different ICU settings, the results obtained were similar. Shoorideh et al. (2015) conducted a cross-sectional study among 12 ICUs in academic hospitals settings. The purpose was to study the relationship between moral distress, BO, and turnover among ICU nurses. A total of 159 nurses completed the surveys. Nurses showed a high level of BO among three dimensions: personal, work relations, and patient relations. There was a positive relation between participants' age, working experience, ICU working years, nurse-patient ratio, and BO, which increased the turnover percentage among those nurses with higher numbers in these areas. This was contrary to the findings from Ozden et al. (2002) and Karaniola et al. (2012) who found that the relation between BO (mainly DPS and EE) and length of experience, both in nursing and particularly in the ICU, was inversely correlated.

In addition, Ozden et al. (2002) indicated other factors that may influence nurses' BO symptoms, such as education level and shift duty. They found that nurses holding a bachelor's degree and working shifts (day and night) show high DPS and EE and low personal achievement levels. Karaniola et al. (2012) added that staff nurses had higher EE scores than nurses' managers, head nurses and nurses' assistants.

Overall, these studies indicate that ICU nurses have moderate to high BO symptoms and moderate CS, which may affect their professional and also their personal lives. Further studies need to investigate these issues within ICU settings. One of the common limitations of these studies is that, except for Karaniola et al. (2012), they were all conducted in either teaching or academic centres.

## **Conclusion**

In relation to SCD pain management in the ED, IBDC and ICU has been studied from different perspectives (e.g. patients, health providers) and by analysing patients' records. The main findings of these studies are that patients wait a long time to be treated, and that the recommendations for pain management are not always followed. However, no research has been carried out to study and explain the reasons behind these issues. Most providers have negative attitudes toward adult patients, but applying quality measurement protocols has proven to lead to slight improvements, which needs more investigation. No study has explored pain management of SCD in the ICU setting.

On the other hand, registered nurses working in the ED and ICU usually show moderate level of job satisfaction but when compared with other departments they tend to have low satisfaction. There were several factors that stimulate nurses' CS and CF level such approbation or rewarding, age, education, working hours and shifting. So as to understand nurses' level of CS and CF while caring for a specific condition and the methodological aspects for such a study would be explained in the following chapter.

## **CHAPTER THREE: RESEARCH APPROACH AND DESIGN**

This chapter includes a description of the methodology that has been selected to study Emergency Department (ED), Inherited Blood Disorders Centre (IBDC) and Intensive Care Unit (ICU) nurses' attitudes, compassion satisfaction and compassion fatigue when caring for patients who have pain during a SCD crisis. The chapter also identifies the conceptual and the theoretical frameworks that influence the research design. The methods of sampling, data collection and data analysis also are identified and justified.

### **Statement of the Study**

As identified in the previous chapter most of the research that has been done to study health care professionals' attitudes towards patients with SCD has been undertaken using quantitative research. As not all human behaviour can be explained and understood through numbers and statistics, a qualitative study to explore and describe nurses' attitudes and experiences in caring for people with pain associated with SCD crises was needed. Also needed was some qualitative data about the effects of caring for these patients on nurses' satisfaction, compassion fatigue and burnout.

### **Research Aims**

The aims of this study were to:

- Explore and describe registered ED, IBDC and ICU nurses' attitudes and experiences in the pain management of patients with a SCD crisis; and
- Identify this group of nurses' level of compassion satisfaction and compassion fatigue, associated with these experiences.

### **Research Question**

What are ED, IBDC and ICU nurses' experiences, attitudes, compassion satisfaction, and compassion fatigue associated with the pain management of patients with sickle cell disease crisis in Saudi Arabia?

### **Research Objectives**

The research objectives are stated below.

- To identify and describe registered nurses' experiences of caring for patients with painful crisis associated with SCD.

- To identify and describe the registered nurses' attitudes to caring for patients with painful crisis associated with SCD.
- To identify the degree of compassion satisfaction and fatigue that might be present in registered nurses as they care for patients with pain associated with SCD crisis.
- To describe registered nurses' perceptions on how they keep on providing care to patients with pain secondary to sickle cell disease and manage their own attitudes and personal responses to the burden of care.

## **Conceptual and Theoretical Framework**

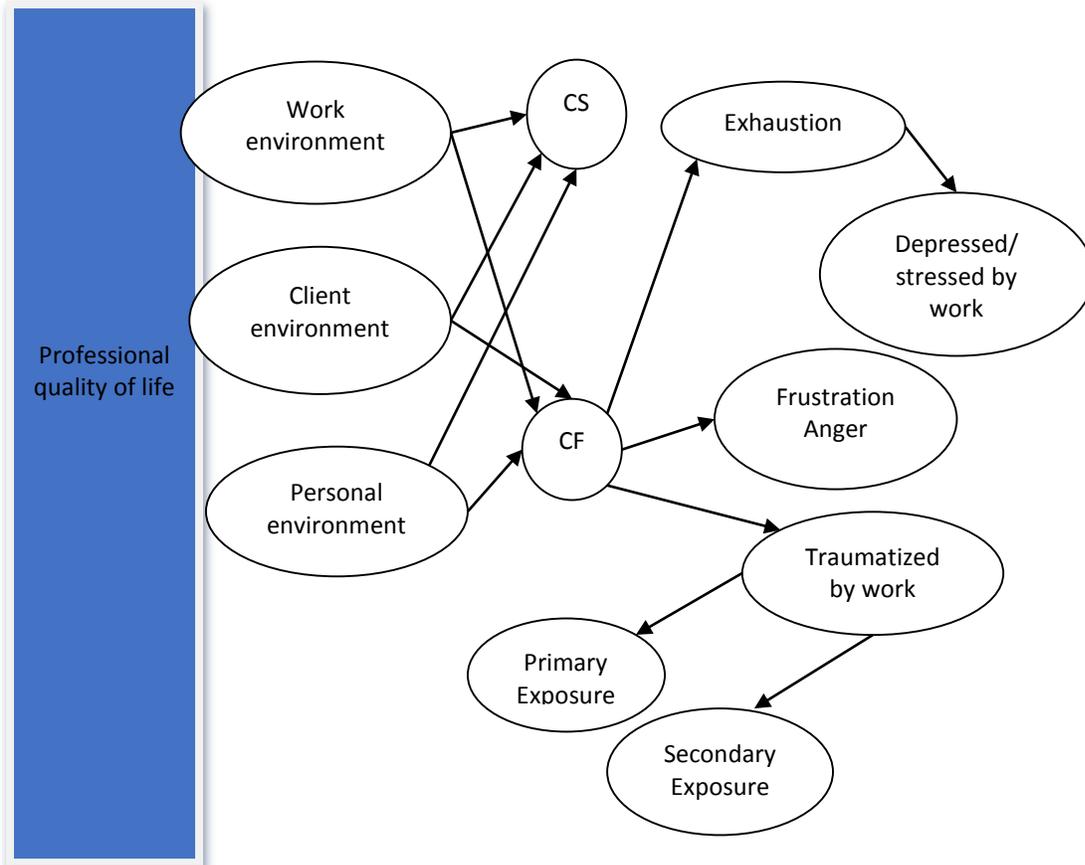
This descriptive study looks at nurses' attitudes towards pain management for SCD crisis, as well as their levels of CS and CF. The interest in nurses' attitudes towards pain is derived from intensive reading to previous studies in the same field, while the compassion satisfaction and compassion fatigue theory is derived from Stamm (2010). The ED, IBDC and ICU are three of the busiest departments in the hospital setting. Treating patients in pain is likely to be a traumatic event, which is why nurses' compassion satisfaction and compassion fatigue was studied as well.

Based on Stamm (2010) there are two main reactions resulting from helping other people either positive feeling or negative one. In relation to the professional quality of life these has been described as compassion satisfaction (positive) and compassion fatigue (negative). Stamm (2010) has proposed that several factors (as shown in Figure 3.1) have been found to affect the level of compassion satisfaction and compassion fatigue these are: the work environment (which is either the department itself or the whole organisation), the client environment (which can be also described as the patient's status or condition), and the personal life of the health worker himself/herself.

In this descriptive study the researcher wished to describe nurses' experiences and attitudes in relation to caring for patients with SCD during painful crisis in the ED and IBDC or after being admitted to the ICU. Nurses' attitudes are defined as the way nurses think and behave while providing care to SCD patients during painful episodes. In the previous chapter it was identified that previous studies have highlighted some factors that may influence nurses' attitudes; these include knowledge, number of patients being treated at one time, the patient's age (paediatric or adult) and the nurses' level of experience. This is represented in Figure 3.2, which diagrammatically reveals the conceptual framework for the study. The conceptual framework combines aspects of registered nurses' experiences and

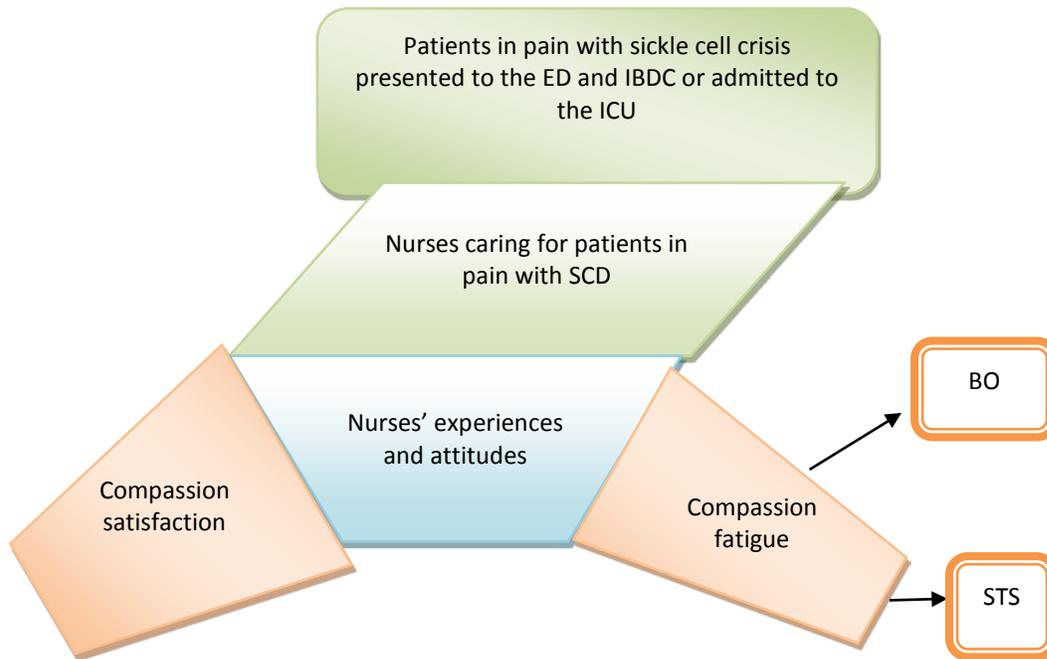
attitudes in caring for patients with SCD; and also the state of their compassion satisfaction and compassion fatigue in care for these patients.

**Figure 3.1 Stamm's Framework for CS and CF**



© B. Hudnall Stamm, 2009-2012. Professional Quality of Life: Compassion Satisfaction and Fatigue 5 (ProQOL). (Used with permission [www.proqol.org](http://www.proqol.org))

**Figure 3.2 Conceptual Framework of the Study**



### **Qualitative Description as the Research Approach**

An informed qualitative description of nurses' attitudes towards and experiences in the care of patients with pain associated with SCD crisis was needed. In addition some description of these nurses' level of compassion satisfaction and compassion fatigue was needed.

Qualitative description was the methodological approach of choice. Qualitative description as a methodology was described by Sandelowski (2000) in her seminal paper published in 'Research in Nursing and Health' journal. It is one of the qualitative research approaches that use low level inference in interpreting individuals' thoughts, experiences and attitudes in understanding a social situation. It basically depends on collecting rich narrative data from participants and analysing this by using broad content analysis and thematic analysis methods (Holloway & Wheeler, 2010; Speziale & Carpenter, 2011).

Sandelowski (2000) states that qualitative description is an aspect embedded in all traditional qualitative research designs such as: phenomenology, grounded theory, ethnography and narrative in which the required phenomena has been advanced through deep interpretive analysis for the collected data. For these traditional qualitative approaches the descriptive phase is a step in developing their work. But qualitative description can be used as a methodological approach in its own right, "producing a complete and valued-end product in itself" (p.335). Sandelowski (2000) describes qualitative descriptions a standing method that can be used to collect in-depth data from participants' experiences but without comprehensive interpretation. This approach is used when initial description of a phenomenon is needed. The aim of using qualitative description is to present the actual meaning of the data as it has been presented from participants without further or in-depth interpretation such as when formulating a theory.

In the following sections the methods of data collection, data analysis and for achieving research rigour are identified. The research procedures associated with qualitative description as described by Sandelowski are incorporated into these sections. References to other sources where relevant have also been placed. Most of the research that has been done to study health care professionals' attitudes towards patients with SCD had used positivist approaches and these have resulted in identification of the problem/phenomenon to be studied. This research study provides qualitative descriptive data and analysis and it is small in scale. It is anticipated that the results will provide a useful basis for further studies in different contexts in Saudi and in other countries.

## **Study Design**

This section is mainly concerned about describing the setting of the research, the inclusion criteria for the study, and the sampling methods that were used for finding suitable participants to study the required phenomena.

### **Study Setting**

This study has been conducted in one of the Ministry of Health acute hospitals, located at the Eastern region of Saudi Arabia, with 365 beds capacity. Nursing staff from the adult ED, IBDC and ICU were the focus of the study. According to personnel from the nursing director's office at the hospital, there are approximately 143 nurses working in the targeted departments. These three acute care units were chosen because the ED and the IBDC were the first place where patients with SCD crises seek help for

pain relief; while the ICU was the unit patients were admitted to when they had an uncontrolled episode of pain with severe complications, such as chest syndrome.

In relation to SCD, ED provides management for female, paediatric, pregnant women at any level of pain and male adults who present in a critical condition. Alternatively for male adults who have complaints of pain or other symptoms from SCD they have to register in the IBDC to get their assessment and management.

## **Sampling Procedures**

Registered nurses working in the ED, IBDC and ICU departments who have had experience caring for patients with pain secondary to SCD crisis were the population of interest for this study. A purposive sampling method was used in this study (Sandelowski, 1995; Pope, Royen, & Baker, 2002) to recruit eligible nurses to gain rich, descriptive qualitative information about the phenomena of interest.

Choosing the purposeful sampling technique aimed to find the suitable source of people who would provide sufficient information about the studied phenomenon. Sandelowski (2000) suggests that any purposeful sampling techniques can be used in descriptive qualitative research.

Ten registered nurses work in ED, IBDC and ICU, were interviewed to gather the data. They were recruited as following: seven from the ICU, two from the ED, and one from the IBDC. The majority of the participants were from the ICU department due to the difficulty in recruiting and interviewing nurses from the two other departments. Although the researcher used snowballing technique during recruiting participants from ED and IBDC it was not successful for achieving higher numbers in recruitment. Some potential participants from (ED and IBDC) agreed to participate in the initial meeting and then they withdrew prior to the interview. These recruitment outcomes have been identified as limitation of the study.

Sandelowski (1995) and Cleary, Horsfall and Hayter (2014) stress that sample size can impact on the quality of data collected. Too small sample may risk reducing the depth of the data, while too large sample could end in superficial data, which is against the aim of qualitative researches.

Registered nurses were selected based on the criteria for their understanding of the English language, their professional work experience (at least one and half years since registration) and their experiences caring for adult patients with pain secondary to SCD. The reason behind the recruitment is that in Saudi Arabia, nurses in their first year post-registration are usually not allowed to make care decisions on their own while caring for patients. On the other hand, there are several foreign nurses who may have

different experience in their home countries. So the main criteria is for those nurses who work in ED, IBDC or ICU to have at least 18 months post-registration professional experience, and to have cared for patients with pain secondary to SCD crises in the relevant department. For the ED nurses, I was informed by the nurse manager that more than half of the staffs were relatively new and that for these staff members their clinical experience varied between two to nine months. Because of this there might have been some difficulty recruiting staff with sufficient experience from the ED.

## **Procedures**

A detailed description about the process of accessing the site of the potential research and the procedure to reach potential participants, the process of advertisement and participants' recruitment from the three departments, the information sessions and how they would be held are being discussed under this section.

### **Site Access and Recruitment**

An approval for the study had been gained from Monash University Human Research Ethics Committee (CF15/11-2015000054, Appendix 4) followed by obtaining the Ministry of Health research committee approval in SA (15-191E, Appendix 5); permission was also given from the intended hospital to proceed with the data collection process (Appendix 6).

After gaining the approval from the hospital, I contacted the Nursing Director to have the departments' supervisors and head nurses' agreements to contact the registered nurses and to proceed with the recruitment and the information sessions. Three information sessions had been held in the ICU where all the department nurses knew about the project. For ED it was a different situation due to the difficulty in gathering all the nurses in one area, so I had to go through nurses' various locations and explain the project for each of them. Two nurses who were interested to participate did not meet the inclusion criteria due to their limited professional experience (three months only). In the IBDC, I held three information sessions with most of the registered nurses working there, and two of them agreed to be interviewed. The participant's information sheet was distributed during these sessions (Appendix 7). This sheet included my contacts details for those who would like to have more information or private conversations about the project. A consent form (Appendix 8) and an information sheet with full details about the study were handed to participants, the potential benefits and possible risk had been outlined as well. All registered nurses working in ED, IBDC and ICU who had more than 18 months professional

experience and who cared for patients with SCD during painful crisis were invited to be part of this study.

In the ICU department the interviews took place in a classroom within the department which was private and locked. The ED and the IBDC interviews were held at various locations within the units because participants were not able to leave their work locations.

### **Recruitment Process Challenges**

There were several factors that influenced recruitment. Time was one of the challenges that affected accessing the site for the study and the recruitment process. The time frame allocated for data collection data in SA was one month only. When I went to proceed with the information sessions, 50% of the hospital staffs were not working (due to a religious calendar event) and I was advised by the nursing manager to wait for another week until the nurses returned to work. After presenting the information sessions, there were some issues with organising the nurses to take part in the study. Most of the registered nurses showed their interest in participation, yet after setting the time for undertaking and recording the interview, some nurses did not show up, and others declined at the time of the interview without explanations. It was more difficult when recruiting ED nurses due to their load of work and the unexpected events that happen any time. When my time to recruit was 'running out' and insufficient nurses were being recruited from ED and IBDC, I undertook more interviews with ICU nurses. Therefore, the majority of the participants were from the ICU.

### **Data Collection**

The required data for fulfilling the goals of this research required two types of data collection. In this section the rationale and methods for both types of data collection are explained. The process of the semi-structured interview and the interview guide are discussed. The final part of the interview involved participants undertaking a self-scoring version of the 'Professional quality of life' questionnaire. This is explained and comments about the validity of the tool are made.

### **Individual Interviews**

A semi-structured interview method was used for collecting the study data. Interviewing participants may be considered the most common form of data collection in qualitative nursing research (Holloway, & Wheeler, 2010; Speziale, & Carpenter, 2011; Treacy, & Hyde, 1999). In qualitative description the emphasis is on participants' experiences and what they know in relation to the research and obtaining a

suitable setting for conducting the study. As Sandelowski (2000, p.338) describes it as, “typically directed to discovering the who, what and where of events or experiences or their basic nature and shape”. Galletta (2013) explores the use of semi-structured interview in order to address the specific phenomenon that is related to the research topic. The structure in proceeding semi-structured interview strategy allows participants to offer new meaning to the study topic. It allows the researcher to attend critically and deeply in the studied subject. It also gives researcher space for asking questions for clarification.

All the interviews were digitally recorded. When participants requested, the digital recording was paused during the interviews, these were usually when sharing things that they did not want recorded or used in the study. Researcher reflections and notes were taken immediately after finishing each interview. Each interview took between 45 minutes to 80 minutes, this included both answering the demographic questions, the ProQOL 5 questions, and the semi-structured interview questions. This length in duration of an interview is supported by Speziale and Carpenter (2011).

Some demographic information from each participant was obtained related to their age, nationality, level of education, professional experience as a nurse and their experience in the current place and their workplace. The interview was used to obtain nurses’ experiences around the following primary areas:

- Participants were asked to share pertinent stories and experiences, as well as their insights regarding how they and others care for patients with pain secondary to sickle cell disease.
- Participants were asked for their perceptions of their own and other nurses’ attitudes in caring for patients with pain secondary to sickle cell disease crisis.
- Participants self-scored their own degree of compassion satisfaction and fatigue (using the ProQOL 5 questionnaire and self-scoring tool).

The interview aide memoire that was used by the researcher and shared with the participants is presented in Appendix 9. As this was a sensitive topic and some participants had personal experiences of losing their relatives due to SCD and when other participants cried due to remembering such conditions, the researcher made it an option to reflect or not to reflect on their ProQOL scores at the completion of the interview.

### **The ProQOL 5 Self-Administered Questionnaire**

This questionnaire was developed to measure workers’ positive (compassion satisfaction) and negative (compassion fatigue) feelings in relation to their work as helpers for other individuals. This is the fifth

version of this tool, and it contains 30 items with two main scales namely compassion satisfaction (CS) and compassion fatigue (CF). CF has two subscales which assist measurement of people's burnout (BO) and secondary traumatic stress (STS) levels. (Appendix 10) The self-administered and self-scoring version of questionnaire was used during the interview, and formed part of the interview process. This self-score tool was chosen as part of the interview process with the registered nurses, to assist them to discuss their perceptions of their compassion fatigue and compassion satisfaction in respect of working with people with sick cell crises characterised by pain. The idea was to encourage them to talk about their perceptions, then to share and discuss what the self-score measure reveals, and their thoughts about whether the findings from the self-score measures regarding their levels of CS, BO and STS offers them other insights or generates any other comments. The self-score tool is validated in English and frequently used tool in measuring workers CS and CF. As English is the official language for these participants in their professional workplaces, the English version was considered appropriate. There is no validated Arabic language version of the tool.

In respect of the questionnaire and the key concepts, the following information is pertinent. CS is the good feeling that a person experiences when doing something that he/she likes or when helping those in need. It represents the individual's ability to adapt to different situations and believe that he/she is making a difference in his/her own or others' lives. This scale comprises 10 items with a total score of 50 (the SD is 10 and Cronbach alpha is 0.88); a Likert scale is used to rate the frequency related to each item from 1 to 5 (where 1 = never and 5 = very often). In interpreting the result scores, less than 22 represent low CS, 23–41 infers average CS while more than 42 indicates high CS (Stamm, 2010).

CF on the other hand refers to the negative feelings derived from providing care or help to other people. There are two subscales for CF: BO and STS. BO represents unhappy feelings resulting from heavy environmental work that is exhausting, either due to personal or work factors. There are 10 items of which five needs reverse scores (numbers 1, 4, 15, 17, 29). The total score is 50 points (the SD is 10 and the Cronbach alpha is 0.75). A score of less than 22 means low BO, 23–41 shows moderate BO and more than 42 indicates high BO (Stamm, 2010).

STS is the third part of the scale and shows the effect treating traumatized patients has on caregivers. It is characterized by reports detailing an ability to sleep, thinking about patients' conditions or avoiding remembering the trauma event(s). This 10-item scale has a total score of 50 (the SD is 10 and the Cronbach alpha is 0.81). Low STS is indicated by a score of 22 or less, moderate STS scores 23–41 while 42 or more represents high STS (Stamm, 2010).

According to Creswell (2009) Cronbach's alpha of above 0.7 in each scale is acceptable among different scales of an instrument that measure various phenomena of interest. The English version of ProQOL5 was used in this study. It has three scales, and each one measures different and separate components. The inter-scale correlation with compassion fatigue for both scales is 2%, while the shared variance between them is 37%, which represents the fact that although they share some variance, each scale has its own measures (Stamm, 2010).

The ProQOL 5 survey items were explained to the interviewee at the beginning of the interview sitting and it was attached to the explanatory statement and the consent form. It was then handed to the participants to answer the questions. After completing the interview, the questions were scored by the researcher, and the participants were informed of the results. There was an agreement between the researcher and the participants related to this part, the researcher would email the participants with their score and if any of them would like to have another session to talk about their results but none of the participants replied to this request.

## **Data Analysis**

This part of the methodology provides an explanation to the methods of analysing the collected data starting from the transcription process till the final phase of the analysis. Additionally, a description of the content and thematic analysis process that had been used during the analysis process was included.

### **Interview Data**

The interview data had been analysed individually and then studied collectively across all participants. The recorded interviews were sent to a professional transcription office in Australia. Then the transcribed data was read several times while listening to the digital recording at the same time so the researcher would be familiar with the data as a whole. After being familiar with the data, line by line analysis of each transcript started. The analysis process started by identifying the research questions, the conceptual framework, as well as the main objectives of the research. This helped the researcher to identify the required data that answered the research questions. Coding took place in each interview transcription and the similar codes were grouped as subthemes gathered under the main themes. Multi-coloured pens were used to distinguish between different codes and to make it easier for the researcher while grouping the codes.

Qualitative content analysis with low level thematic analysis was the chosen data analysis strategy in qualitative descriptive research (Sandelowski, 2000). It is a process of analysing the collected data either through interview or observation to summarize the information throughout the collected data.

Qualitative content analysis differs from quantitative analysis in the process of establishing codes and themes. In quantitative research, researchers often use a “pre-existing set of codes to the data” (p.338) while qualitative researchers usually depend on their data to pick up the most essential and proper codes and themes that present the meaning of the data. Low level thematic analysis is considered as the “least interpretive of the qualitative content approach” (p.338) because it should be presented as it is without the deep interpretation that is often undertaken in more traditional interpretive qualitative studies (e.g. phenomenology, ethnography). Sandelowski and Barroso (2003) argue that in different qualitative methodologies the analytic process moves from simple description to a deep interpretation of the phenomena. In qualitative description the level of interpretation is kept descriptive and at low level inference. “Conceptual/ thematic description” (p.913) is the term that has been presented by the authors to represent the process of obtaining codes and themes from the collected data rather than using themes from existing theories. Furthermore, Vasimoradi, Turunen, and Bondas (2013) report that content analysis and thematic analysis are the chosen analysis styles in descriptive qualitative approach. Although, they are sometimes used by researchers interchangeably, a comparison between both content analysis and thematic analysis is presented in relation to the definition, the aim of the analysis, philosophical background and process of analysing data. See Table 3.1 below. To construct this table I have drawn from Elo and Kyngas (2008) and Vaismoradi et al. (2013) some key principles and processes associated with content analysis and thematic analysis that will be used in this study.

**Table 3.1 Principles and Methods of Content and Thematic Analysis**

Type of analysis	Research Processes
Content analysis	<p>Systematic descriptive coding and categorising to explore large amount of text by tracking words, lines, key messages for their frequency and the relationships between them.</p> <p>It is usually used to explore nursing phenomena where little is known about it by presenting common matter in the data.</p> <p>Three phases in content analysis: preparation, organisation and reporting. Preparation means to choose an analysis unit either a word, a phrase or sentence which can be done after several readings to the data and being familiar with it. Organising means to develop the open codes and categories through reading the text and adding notes or headings. Collecting similar categories under one heading and finally, reporting the result either through conceptual system, a model, and categories.</p>
Thematic	It is a method of identifying, analysing and presenting the pattern within the data.

analysis	<p>The result is presented with less description and more interpretation of rich and complex data.</p> <p>Thematic analysis has six steps to be conducted which are: 1) being familiar with the data by reading it several times, 2) coding throughout the entire data 3) then gathering similar codes under a theme, 4) after providing initial themes checking if they match with the entire data and extracted codes or not, 5) after matching codes with themes defining themes is the next step by giving a clear definition of each theme and giving them names, 6) the final phase is reporting the results according to the research question and reviewed literature.</p>
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## ProQOL 5 Data

As the researcher I scored the participants ProQOL 5 results using the self-score instructions from the questionnaire. These include first converting items 1, 4, 15, 17 and 29 to 1r, 4r, 15r, 17r and 29r, as explained earlier. The second step is to find the sum items for each scale. The last step is to convert the 'z' score into an 'r' score, with 50 being the mean raw score and 10 being the raw standard deviation (Stamm, 2010). In addition, each participant had her ProQOL 5 data and outcomes linked or paired with her individual interview data; this data had been treated as descriptive and they were combined during the analysis.

## Validity and Trustworthiness

In 2005, Milne and Oberle described four components of rigor for qualitative studies [these were based on earlier work by Whitemore, Chase and Mandle (2001)]. Credibility, authenticity, criticality and integrity are the four components.

Credibility is a core component of research rigor and trustworthiness. Credibility means evaluating whether or not the collected data and research process is trustworthy, and whether the transferability refers to the possibility of using the results in similar settings (Graneheim & Lundman, 2004).

Sandelowski (1986) describes credibility as presenting people's experiences truthfully so that other people who have gone through the same experiences can identify with the results. In addition, a study is credible when acknowledged by other researchers or readers when they face the same experience or situation as that which is being described. Trustworthiness is not only concerned with presenting the truth, but also depends on the researcher's ability to present his/her role in the research honestly. It depends on a clear illustration of the researcher-participant-data relationship. In the context of research, integrity means to conduct a study with an honest and clear research process that shows the relevance path along with the aims, research design, sampling techniques, data collection strategy and data analysis process (Polit & Beck, 2010). Criticality is one of the primary principles applied in qualitative research. It indicates that the researcher has conducted a critical evaluation of each decision

taken within the research period (Polit & Beck, 2010). Transferability refers to the ability to apply the research results to settings other than the studied place (Shenon, 2004). In qualitative research, the researcher would make the decision whether or not the research methods, its process and outcomes could be applied to other settings.

Credibility had been shown by presenting participants' experiences as told without deep interpretation. Authenticity was achieved by supporting the participants to speak freely during their interviews and by giving them a chance to tell their stories and express their feelings. Additionally, integrity has been shown by the provision of a full description of the research process, including a detailed explanatory statement for the participants, information regarding the interview process, an accurate presentation of the results without omitting any part of the results and the maintenance of the privacy and confidentiality of the participants during the whole process. Criticality had been achieved via critical analysis and thorough review of the analysed data (codes and themes) so that the results could be presented truthfully and accurately.

Sandelowski (1986) indicates that transferability eventually rests with the consumers of the research as the final decision can only be made by those who have read it. In addition, the researcher should work to ensure sufficient transparency so as to maximise transferability. Sandelowski (1986) recommended that the following measures be undertaken by qualitative researchers to create conditions for optimum transferability: the current study findings should "fit" (p. 32) when applied to similar situations other than the study itself, the findings should present basic grounded data about the studied life experience (phenomenon) and the participants should agree with the researcher about the meaningfulness of the findings.

## **Ethical Considerations**

In the following sections, the principles of the ethical consideration that were applied to the research are discussed; particular ethical considerations for qualitative research are identified and a description of the approvals gained for the research is presented.

### **Values and Principles of Ethical Conduct that Apply to all Human Research**

There are certain values and principles to be taken in consideration when planning a research study and particularly when humans are involved in it before getting the approval from any research ethics committee (Holloway & Wheeler, 2010). There are certain points to be addressed in the application

form in order to achieve the acceptance phase of a research. The main principles for any research are integrity, respect for human being, justice and that the research is beneficial (National Health and Medical Research Council [NHMRC], 2014).

Integrity and merit in the study are essential aspects; and these were achieved by involving expert personnel in the research, designing the study in way of matching all its parts starting from the aim, choosing relevant literature and the suitable method to end up with strong and valid results. Respect for humans is another aspect to be considered when involving participants. The research team was composed of mixed experience and expertise. The student researcher was a novice in research, but an experienced RN who had been working in similar situations to those being researched. The supervisors were experienced in the research methodology and research methods.

Registered nurses who met the inclusion criteria were free to either participate in the study or not, it was clearly stated that the participation was optional and there would not be any consequences against those who did not agree to be part of the study or for those who would like to withdraw. None of the participants asked for withdrawal from the study. Participants were given code-numbers for the purpose of maintaining privacy and confidentiality. They were coded from participant one to participant 10. This coding was known by the research team only.

Respecting the participants' autonomy was sustained by freedom of choice in participation, by freedoms to choose what was said during the interview, and by freedoms to choose what was recorded during the interview. Researchers also had respect for the national laws and regulations in the country and the site where the research took place, and for local customs and cultural norms. Respect was shown through presenting the research information with simple and understandable language for participants, providing participants with a copy from information sheet and consent, giving them full information about the study and answering their questions until they were satisfied with what had been explained. Cultural and language barriers were also taken into consideration.

Justice in research involves fair selection of participants based on the inclusion and exclusion criteria and not on the benefit of the researcher. Researchers should perform their studies based on the approval from the research committee and if there is any changes in the procedure or the use of the data another approval should be obtained and further consent from participants explaining the changes has been made, reasons behind this change and the possible benefits and risks that may occur due to the change. Inclusion and exclusion criteria were set according to the aim of the research and to find suitable

participants who will answer the research question and help to gain rich information in relation to the studied phenomena (NHMRC, 2014; Schneider & Whitehead, 2013).

Beneficence is about the benefit of the study for the participants or for a wider community. It is not only the benefits but also to identify the possible risks from performing such a study on participants either physical, social, psychological harm or revealing their rights as human. During designing any study researchers should consider minimum risk to participants while achieving the goal of generating good knowledge, improving performance or patient outcomes, as well as improve the quality of care being delivered. These benefits and risks should be explained to the participants and they should be included in the consent form as well. These elements should be explained even if they are being written but a researcher has a role to make sure that participants understand the written information. Beneficence was judged by the researchers in designing the project, and the arguments for this were presented to the relevant ethical committees, that were satisfied with both the design and the arguments.

Informed consent is an ongoing process throughout the project and should be obtained when humans were the subject of any study. It was designed to provide participants with full exposure to the study, including the project aim, the potential risks as well as benefits for both participants and community, what was expected from them as participants and a description of their rights, including free participation or withdrawal from the study (Wiles, 2012). The aim of providing this information to participants was to ensure their understanding of the project, in addition to their rights, before deciding to participate. The researcher should identify how much participants need to know, how this information should be delivered and how to make sure that participants understand the information presented (NHMRC, 2014). For this study, these considerations were applied, and all information about the study was written in simple and understandable language.

Identifying risks associated with research is an essential ethical aspect. Risks can be classified as harm, discomfort or inconvenience reactions. It involves describing the type of harm (physical, social, psychological, legal or economic), the severity of the harm and its consequences (NSECHR, 2014; Wiles, 2012). On the other hand, identifying potential benefits of the study is a basic principle in research that not only clearly defines the potential contribution of the research to improving lives, on the individual level, community level or both, but it also assists the research committee review board when deciding whether to approve a project. A balanced presentation between risks and benefits where the benefits are greater than the risks is the key to project approval.

Although it is the duty of the research committee to identify if the study is worth the risk, participants also have the right to agree or disagree with the committee's decision. In our study we stated the benefits from conducting this study, which will help us to improve the care being delivered for patients with pain associated with SCD crisis and its effect on their compassion satisfaction and compassion fatigue. Participants had the opportunity to reflect on their practice and share their experience. On the other hand, recalling a painful and sad memory which might be associated with treating pain might create emotional discomfort for participants. Care was taken regarding this, for instance one of the participants became emotional and cried during the interview, however she refused to pause the interview and she insisted to continue it as she was insistent that she wanted to share her thoughts and experiences.

### **Ethical Considerations in Qualitative Research**

In addition to the above discussed ethical principles that should be applied to all research studies, there are certain concepts to be addressed specifically for qualitative research, which are privacy, anonymity, confidentiality and use of the results. Privacy means ensuring that the participants' personal information is kept private. Coding is a method of maintaining participants' privacy in the process of transcription and presenting the final result. Confidentiality is an agreement between the researcher and participant about who will have access to the obtained information and how it would be presented. There is a possibility of accidentally breaking confidentiality by using quotes if they are not being presented carefully (Harding, 2013; Allmark et al., 2009). Quotes were presented in ways that preserved these considerations.

Informed consent was obtained from participants by their agreement to participate in the interview, and written consent was signed before starting the interview. Anonymity was not possible because of the personal meeting with the participants and the researcher. However, confidentiality was applied while transcribing and presenting the results of the study by coding and judicious use of quotations.

### **Process of Research Governance and Ethical Review**

This process started on January 2015 when we applied to Monash University Human Research Ethics Committee (MUHREC) a low risk application form completed according to the committee standards. An approval to conduct the study had been sought from Monash University's Human Research Ethics Committee number (CF15/111 – 2015000054) to be conducted within five years from March 2015 till March 2020. Then an approval was sought from the research committee by the Ministry of Health in

Saudi Arabia with approval number (IBR Log 15-191E). However identifying details pertaining to the organisation in which the data was collected have been 'covered over'.

## **Conclusion**

This chapter included a description of the methodological approach that was chosen to conduct the study. A descriptive qualitative approach was used to explore nurses' experiences and attitude toward patients with SCD when treating painful episodes. The descriptive qualitative approach was based on Sandelowski's principles and supported from other authors' perceptions where applicable.

A description for the ProQOL 5 has been presented. The process of the ethical approval has been explained and the process of recruitment as well as the process of interviewing ten registered nurses had been explained with a brief presentation to challenges that I faced during recruitment process. The collected data was analysed by qualitative content and thematic analysis. The results from this analysis are presented in the next chapter.

## CHAPTER FOUR: RESULTS

In this chapter the results of the interviews with the registered nurses are presented. In the chapter the three themes identified in the analysis are identified and discussed. The themes are: participants' experiences of caring for patients with pain associated with SCD, participants' attitudes toward patients with SCD during painful crises, and the participants' degree of compassion satisfaction and compassion fatigue. The chapter is commenced with details of the participants and their demographic data.

### Participants' CS, CF and Demographic Data

A total of 10 registered nurses who work in the three targeted clinical areas that concern managing patients with SCD during painful crises were interviewed between 26<sup>th</sup> of July 2015 and the 13<sup>th</sup> of August 2015. All the participants were female. The participants' ages ranged from 26 – 38 years with a mean age of 32 years. The extent of their professional experience ranged from two to 17 years with mean of 9.5 years. The participants' educational qualifications were distributed between diploma holders (30%), high diploma holders (20%) and bachelor degree holders (50%). The difference between the diploma and high diploma qualifications is the number of years, diploma holders usually have two years of theoretical study and six month practice, while high diploma graduates have three years theoretical study and six months practice. A summary of the key demographics is presented in Table 4.1

**Table 4.1 Participants' (n=10) Demographics' Information**

Age		Workplace		Highest Professional Qualification	
25 - 30 years	4	ED	2	Diploma	3
31 - 36 years	4	ICU	7	High Diploma	2
37 – 42 years	2	IBDC	1	Bachelor	5
Mean age (years)	32				
<b>Total Professional Experience</b>		<b>Current Clinical Placement Experience</b>			
2 – 5 years	1	< 2years	1		
6 - 10 years	6	2 – 5 years	5		
> 10 years	3	> 5 years	3		

All participants also completed the ProQOL 5 questionnaire. When answering this questionnaire the participants were instructed to answer the 30 questions in respect of their feelings and experiences in the past 30 days about working with patients who had a painful SCD crisis. In Table 4.2 the results for each participant in respect of their levels of compassion satisfaction and compassion fatigue are presented. This information can be read in relation to direct quotes from these participants that are presented throughout the chapter.

**Table 4.2 CS and CF Results for Each Participant**

Participant number	Compassion Satisfaction (CS)	Burnout (BO)	Secondary traumatic Stress (STS)
P 1	High (47)	Low (20)	Low (19)
P 2	Average (40)	Average (29)	Average (28)
P 3	Average (28)	Average (32)	Average (26)
P 4	High (45)	Average (26)	Average (30)
P 5	High (43)	Low (17)	Low (12)
P 6	High (43)	Low (22)	Average (26)
P 7	High (44)	Average (24)	Average (30)
P 8	Average (38)	Average (24)	Average (25)
P 9	Average (39)	Low (22)	Average (24)
P 10	Average (37)	Average (27)	Low (21)

As this information is also important as summary, in Table 4.3 the summative results for the group in respect of their CS, and CF (as BO and STS) are presented.

**Table 4.3 Percentages of CS, BO and STS Among Participants**

		High		Average		Low		Total
<b>CS</b>		n= 5	50%	n= 5	50%	----	----	100%
<b>CF</b>	<b>BO</b>	----	----	n= 6	60%	n= 4	40%	100%
	<b>STS</b>	----	----	n= 7	70%	n= 3	30%	100%

All participants had either average or high levels of CS. Most of the participants shared during their interviews aspects that were satisfying about being nurses and being able to care for people who are in need. It seemed for most of these nurses that positive patient outcome was one of the triggers for nurses' satisfaction. When the outcome of the patient was good and he/she left the hospital healthy nurses felt happy and satisfied. On the other hand, patient death reportedly had a negative impact on

participants. For instance *“I am very happy and I am very proud to be as a nurse.” (Participant 5, L 35).* Participant 2 recalled a patient’s condition that makes her happy with the care had been delivered to this patient with in the ICU. A patient was admitted with SCD critical situation and painful crises *“he was in real crisis; he was screaming out.” (L 317, 318)* and after three days the patient’s condition improved and he went home *“I was really surprised that when he came, he was in real pain, but within two or three days, he was out of ICU and out of crisis. And he went home, the next day” L 328, 337.*

All of the participants had CF that was low to medium in level. This was also true for the CF component scales of BO and STS. Some nurses shared that they were recalling patients’ conditions with SCD even after years from the actual events happening. The participants still remembered the event as if it happened now. Recalling certain patients’ SCD conditions made nurses cry, feel sad, and occupied their minds. For example: *“She died. She was my patient. It was very hard. Until now, I cannot tolerate it. It is very traumatic for me” (Participant 10, L 202, 204).* In the following sections the thematic findings from the interview data are presented.

### **Nurses’ Experiences of Caring for Patients with Pain Associated with SCD**

The participants’ perspectives when talking about their experiences while caring for patients with SCD during their painful crises were mainly concentrated on the issues and challenges in undertaking nursing assessments for pain, the administration of medication, and the provision of psychological support for patients with SCD during painful crisis. These findings are reported below and relevant example direct quotations from participants’ interview transcripts are presented in italics.

### **The Participants’ Experiences of Caring for Patients with SCD Crises**

All of the participants reported experiences of nursing patients with SCD crises. Four of them experienced caring for patients with SCD in two critical departments (participants 1, 3, 4, and 6). They had their experience between ED, IBDC, ICU, intermediate ICU and female medical ward. They had 10 to 12 years of experience caring for patients with SCD. They faced several challenges and situations that had an impact on their professional life. For example, participant 3 described her experience in caring for SCD as *“it was a very terrible experience. Some of them, especially, tried to beat me” L5, 6.* Another participant described the difficulty in managing those patients as the severity of their symptoms and the difficulty in assessing pain for some group of patients.

*"I remember we've seen a baby of only about three years old, crying out in abdominal pain; he was in the middle of crisis. It was difficult to understand him, really. It was too challenging". (Participant 6, L 77, 79)*

Participants indicated that they were very often to care for patients with SCD during painful crisis. The general impact for nurses' experience while caring for patients with SCD had been described as either good experience or bad ones. This depends on the troubles that nurses faced throughout their years of experiences.

### **Pain Assessment for Patients with SCD Crises**

The stories shared by the participants revealed that they and other nurses use different ways to assess their patients' pain. Most commonly the nurses' methods of assessment usually consisted of asking the patient to rate his/her pain or using a facial expression scale which will tell the nurse whether the patient is in pain or not. The participants also shared that nurses tend to assess their patients from their behaviour; for example the patient's posture on the bed, sitting or lying with painful expression, the eating appetite, and the extent of the patient's use of the mobile phone. For example, Participant 2 stated *"According to the pain scale, according to his facial expressions and according to the loudness of his voice"* (L 62, 63).

On the other hand, some participants shared that often nurses do not ask their patients to rate their pain as this is mainly done by the physician, and that many nurses use the facial expression scale assessment only. This was illustrated by Participant 3 who stated, *"To be honest, the doctors are asking the patient, where is your pain? And what is the number out of 10. ... for the nurses, actually, no. We are depending on how we are seeing them [the patient]. And how we are seeing the patient: there is this facial expression scale"* (L 283, 284). Nurses believe that when the patient is talking in their mobiles or eating their meals particularly after receiving the analgesia, it means that those patients do not have actual or real pain.

Moreover, pain assessment may depend on the conscious level of the patient as elaborated by several participants. For a conscious patient, the pain assessment is mainly dependent on asking the patient about the level of their pain, using facial expression scale and pain assessment sheet that is available in their patients' files.

*“For conscious patients, we are also assessing the patient's assessment for themselves. It's good – for our assessment, as nurses and also, for our doctors’ – to take all those three assessments”. (Participant 7, L 148, 149)*

On the other hand, unconscious patients and patients who cannot express their pain depend on the nurses to use other factors in identifying their patients’ pain level, which includes assessing and monitoring vital signs. When a patient’s monitor shows a tachycardia, tachypnoea and patient’s movements these signs indicate that the patient may be in pain. Other nurses added that monitoring patient’s blood work frequently can indicate if the patient is having a painful crisis or not such as a dropping in the haemoglobin and increase in the haematocrit level.

*“For sedated patients? ..... She’s moving. Moving and fighting with the ventilators”. (Participant 8, L 99, 100)*

After performing their assessment, nurses provide pain management as required by the physician’s orders. The participants emphasised their role as following the doctors’ orders when it comes to pain management. The participants were generally agreed that treating pain in SCD is one of the most challenging tasks for nurses to handle, due to the often quick deterioration and fluctuation in the patient’s state which may result worsening the patient’s condition and losing his/her life in a short timeframe.

## **Pharmacological and Non-pharmacological Pain Interventions**

The participants reported that a key goal of pain management is to relieve the patient’s pain, to keep the person comfortable and free from pain. Another goal of the management is to avoid worsening the patient’s condition through providing the accurate care in the suitable time so the patient will not suffer from other complications or deterioration. For example participants stated:

*“I want achieve that the patient would rest without pain. I want to reach to zero level of the pain”. (Participant 4, L 101, 102)*

*“The goal, all patients comfortable after see me, after care. To go to home, not to admission, not to complication. This goal”. (Participant 9, L 109, 110)*

Some participants believed that seeing the patient sleeping on the bed would indicate that the patient’s pain had subsided. Another participant identified that *“when the patient is able to stay on the bed and take his meal it means that he/she is free from pain” (Participant 9, L).*

*“Sometimes if you will see them sleeping, I would feel it’s... They don't have pain. That time”. (Participant 4, L 105, 106)*

There was semi-agreement between the participants in relation to the availability of a written protocol and/or a strategy for pain management in patients with SCD crises. Some participants (5, 6, 7, and 8) identified having and using written protocols that they follow for management of pain in a SCD crisis; other participants (3, 10) do not follow or use these strategies. Most of the participants identified that each patient has his/her own management protocol that is written by the treating physician and they have to carry out the physician's orders. In addition, there is a routine work that has been done for all patients with SCD who come to the hospital which includes accessing intravenous line, extracting complete blood work and starting intravenous fluids. Example quotations from the participants appear below.

*"Yes, obviously, we have the protocols ... I mean, for sickle cell disease...They need hydration, they need opioid analgesics, and they need oxygen". (Participant 5, L 108, 110)*

*"Written protocol, no. But we have the care plan, already. So, we know how to deal with these cases". (Participant 10, L 90, 91)*

*"Actually, we're following the protocol for what our doctor's order". (Participant 7, L 172)*

The participants reported that pain management for patients with SCD depends mainly on the pharmacological administration of several medications, and that this varies between paracetamol, no steroidal anti-inflammatory drugs such as voltaren (diclofenac), weak opioids such as codeine, and strong opioids such as morphine.

*"The routine, giving fluid, IV fluid, given voltaren or paracetamol. Simple medication. After that, with doctor started narcotic, tramal, morphine. Some patients want pethidine". (Participant 9, L 153, 155)*

The participants reported that as nurses they are allowed to administer some medications, except opioids. In the case of patient refusal to take the medicine or he/she is allergic to the drug; as nurses they inform the physician for a new assessment and prescription for the patient's condition. The trigger for treating patients during painful crisis is the patient's condition rather than the existence of protocols. It is not mainly about the protocol, it is all about patients.

*"And we will give them analgesics from least effective to the strongest effect. We are only allowed to give Voltaren, for example, paracetamol, zipho". (Participant 3, L 123, 124)*

The participants shared information that suggests that the route of drug administration differs from one department to another, as this is primarily based on the local policy in each department. For instance, in the ED and IBDC intravenous route of drug administration is not allowed, the frequently used drug administration sites are either subcutaneous or intramuscular. In the ICU the main route of drug administration is intravenously and continuous infusion till the patient's pain is relieved. Once relief occurs, there is tapering down the drug dosage until the infusion can be discontinued. Then drug administration occurs in interval doses every four, six or eight hours, and the unit prepares the patient for being transferred to the medical department or discharged home.

*"It's only in ICU that we are giving IV injection. So in the ward they will start subcutaneous". (Participant 8, L 318, 319)*

*"According to the doctor's order. .... For example, morphine. Sometimes it's Q4 hour, and sometimes it's Q6 hour. ... And sometimes they are starting the morphine infusion". (Participant 5, L 131, 134)*

Most of the participants emphasised the importance of psychological assessment and support for their patients during painful crises episodes. Psychological support measures that they made included talking with patients as elaborated by participant 9 (L 145, 146) *"I tell the patient, I cannot do anything. I am with you, I am here. If you want anything, I have to wait I will do it"*, trying to reassure them that they are okay and they do not have to worry about their pain, that the nursing and medical staff will manage them, and at the same time that they need to focus on something other than the pain. This reassurance was undertaken mainly by the nurses, but it could also be done either by specialised personnel such as a psychological advisors or a social worker. Diverting patient's thinking away from the pain by starting a conversation, providing something to read such as a book.

*"It's also good to include a social worker or psychological advisor or something, just to ensure – all it takes is assurance and talking with them, to make them feel a little bit calmer". (Participant 6, L 234, 237)*

*"They (Doctors) can advise that injection is not the only thing that will disappear the pain. .... I mean you can relieve the pain by something you will do. Reading or just to divert the mind. .... this is psychological suffering for the patient. They will feel pain because they're alone in the room and nobody can talk to them". (Participant 8, L 418, 424)*

Some participants reported that they would also perform massage for their patient because they believed that this was a part of the psychological management as well as being effective in relieving the pain (Participants 8 and 7). Others participants (4 and 9) denied the effect of massage and were against

performing such action, which they believed may increase patients' demands and make them ask for more attention. Beside the massage some participants (1, 3, 6 and 9) would aim to provide hot compression, blankets, comfort and a quiet environment. For example:

*"If she needs me to massage her, I will massage her". (Participant 8, L 268, 269)*

*"Patients need massage, which I cannot do it". (Participant 9, L 312)*

Some participants raised the issue of using advance standing orders as protocols to treat painful crisis mainly when the physician was busy. These advanced standing orders provided some authority for the participants as nurses to administering medications and not keeping their patients waiting until the arrival of the doctor. In addition, these advanced standing orders may aid new registered nurses in understanding the nature of the disease as well as having the required knowledge in the management part.

*"We should have, need more protocols for, especially for patient in infusion, how often we can give bolus even without asking doctor". (Participant 4, L 214, 216)*

*"Professionally ... it is better to have a protocol..... Especially when you have new staff, they don't know what a sickle cell patient is, they cannot deal with them". (Participant 3, L 306, 309)*

Another important point that was discussed by the participants was the need to have clear protocols for admitting patients and treat them aggressively in order not to worsen their condition which may cause patients' death.

*"I think they should start the aggressive management from the beginning, so the patient will not deteriorate and die". (Participant 6, L 453, 455)*

### **Difficulties with Managing Pain in SCD**

Nurses rated their level of care for patients with SCD during painful crisis between competent and expert. This rating was based on their years of experience since they care for those patients and to the number of patients that they cared for. Although the nurses had this rate for themselves, they still found some difficulties in treating and caring for those patients during the pain episode.

*"Maybe competent. .... Because of how many years I have been here, I am also handling many different cases of sicklers". (Participant 7, L 90, 95)*

There were several factors that make pain management difficult especially for patients with SCD. Patients' behaviour toward the medical team including nurses was the first issue. These behaviours

varied between patients' being panicked, shouting, saying bad words, beating nurses or throwing objects on nurses during the painful crisis.

*"But most of them get panicked, when they get to ICU admission". (Participant 6, L 225, 226)*

*"Their (patients) attitudes are very bad, saying bad words. If they can even beat some nursing staff". (Participant 3, L 70, 71)*

Patients were complaining of pain continually and they were not satisfied with the delivered care to them which was indicated by the participants as a difficulty for pain management. This was explained by patients' demands to receive the medication they request, their way of asking for treatment and not accepting what the physician decided.

*"We have ... patients who are coming here and they are thinking the IBDC is like a – not a hospital, it's like a grocery. And they are dealing with the doctor like a grocery seller .....They are asking him, "Give me my injection, now". (Participant 3, L 256, 259)*

Moreover, patients sometimes questioned nurses' performance of administering the actual prescribed drugs or not as illustrated by participant 8 *"They want more. Even if you will give, they are thinking it is saline only, no medicine, they are not believing"* (L 287, 288).

Additional obstacles that might delay the management for those patients include: the difficulty in accessing intravenous line to the patients, most of the patients have small veins or they presented to the hospital dehydrated with collapsed veins which made the insertion difficult and postponed the management process.

Educating patients about the nature of the disease, involving patients in the care or the management plan and teaching patients alternative methods to treat their pain at home were explored by the participants as factors that might improve patient's condition and help in decreasing their visits to the hospital.

*"Really, I've seen many patients. They are fully aware of their disease and they are not coming to the hospital, frequently". (Participant 6, L 263, 265)*

For some nurses language was a barrier when they cared for their patients. It affected negatively the interaction process that took place between nurses and patients. This could affect the education process as well as the management efficacy. Only three, out of seven non Arabic speakers, participants indicated language as a barrier in the interaction process between them and their patients, and some participants

did not see language as a barrier. They could provide their care perfectly even if they were not familiar with the local language. As a solution for this issue nurses tend to ask a physician or an Arabic speaker staff to act as a translator between patients and nurses.

*“Even though I'm not expert in Arabic or English, but I didn't feel any difficulty”.*  
(Participant 5, L 186, 187)

For some nurses the lack of knowledge about the disease itself and the physiology of pain as well as the pain management and the updates in this condition was one of the barriers for effective pain management for patients with SCD. Some participants demanded having a specialised centre to treat these patients for all age groups including pregnant women, paediatric and adult patients. They requested also specialised nurses and physicians, who have speciality in treating SCD, and they required to include other team members in the management plan such as: psychologists, social workers and physiotherapist in order to achieve maximum care for those patients.

*“It's better to have - maybe experienced doctors with new tools ..... But we need another expert. .... We need it from the social workers, we need physiotherapists, and we need psychologists”.* (Participant 3, L 329, 336)

### **Nurses' Attitudes towards a Patient with SCD during Painful Crisis**

The participants shared several important aspects about their attitudes towards a patient who is experiencing a painful crisis in the manifestation of their SCD. These are related to their feelings, the daunting nature of the patient's pain, and drug addiction.

### **Nurses' Feelings While Caring for SCD Patients during Pain Episodes**

Treating patients with SCD during their painful crisis was one of the challenges that nurses face during their work. It was difficult, stressful and hard for them to see their patients crying and complaining of pain while their hands were tighten and they could not administer any treatment without a physician order. It was an unhappy situation that nurses found themselves facing during managing sickle cell patients. Some participants put themselves in the patient's situation and other participants elaborated on spending more time with the patients rather than the other professionals which made it more difficult for them seeing and managing those patients.

*“As nurses ..... we can feel it or we can connect with them, more than the doctors”.*  
(Participant 6, L 99, 102)

Although seeing patients complaining was hard for the participants, some nurses identified their ways of managing such issues by treating patients in an empathetic way rather than sympathetic one, adjusting to the current situation by being strong and not to be affected by the situation, and being busy with other patients which may occupy their minds from thinking about the patient's situation. This adjustment depended mainly on the nurses' experience, the work overload and shortage of staff. Patient's status of being conscious or under sedation also had an impact on nurses' tolerance for managing them.

*"Sometime I feel like patients... Sometime, if there a lot of patients then that's no feeling. .... According the situation". (Participant 9, L 292, 296)*

*"We already know we should not be sympathetic and we should be empathetic while doing the care and all". (Participant 5, L 94, 96)*

*"It will affect my family if I will go with these stress". (Participant 4, L 187)*

### **Daunting Patients' Severity of Pain**

One of challenges that nurses faced when caring for patients with SCD was evaluating the actuality of pain that patients had.

*"It's a really tough situation. Sometimes, we cannot really figure out if it's a real painful crisis or just abuse". (Participant 4, L 117, 118)*

Nurses most often did not believe patients when they complain of pain. When a patient asked for his/her dose in the exact time for their management, nurses thought that this patient was not in pain and only counting the hours to have the medication. Even when the patient said that he/she had pain and nurses perform their assessment and judge that the patient is not in pain so they did not give the required treatment and they preferred to inform the doctor.

The severity of pain was identified usually by assessing the patient's facial expression and talking with the patient. Some nurses passed through patients' old patient file to determine their assessment as well. Taking patient history in relation to pain, its severity, location, the starting time of the pain, the medication used at home and the duration between the starting points until arriving to the hospital was another method that participants used to evaluate patients' pain. Nurses found it difficult to distinguish patients' pain either it was real pain or acting just to get the opioids dose.

*"A sickle-cell patient will come to you, she's in pain. By assessment from her face – pain assessment – talking to her, we know that she's in severe pain". (Participant 1, L 377, 379)*

Nurses varied in their explanations for patients' pain and their tolerance to the pain. Some nurses believe that patients' tolerance to the pain differs from one patient to another which makes it hard to distinguish whether they are in pain or not. Others believe that some patients from the recurrent use of the analgesia, their body becomes used to the required dose so it is not effective any more.

*"Most of the patients sometimes, they already immune to this painkillers. So they want high dose". (Participant 8, L 275, 276)*

### **Nurses' Views about Drug Addiction Among Patients with SCD**

The fear from addiction and giving patients a narcotic overdose were noticed as the main concern from the nurses' perceptions. There was a belief among ED personnel that giving patients opioids drugs intravenously would lead to addiction as well as giving narcotic as a first choice of drug for those patients which might lead to addiction.

*"Yeah, IV narcotic, because lead to patient addiction". (Participant 9, L 184)*

There were certain factors that may influence nurses' thinking or identification for addicted patients among SCD sufferers who seek pain management in the hospital such as: the frequency of admission, knowing their medication, calling for their doses when it was due, their ability to distinguish between their actual medicine and other medications. Nurses distinguished patients into two categories true patients who had real pain, and those who were acting to have pain. Some patients have been put on a black list as identification for those patients as drug addicts.

Some participants judged patients as addicted by their behaviour while seeking hospital care either by specifying their medication and the usual dose they had, or by the opioids needed in the pain management however they are not the only medication for treatment and patients have to be educated in relation to this issue. Some participants said that some patients asked for opioids not to relieve their pain but it was for a relative with social or psychological problems. As described by some participants, there were some patients who came to the hospital when they faced social, personal or psychological problems and they could not handle them, so they would visit the hospital and asked for medications or sometimes they would ask for IV fluid and a place to sleep in.

*"Most of the time, they are not in a good social or psychological condition and they are not that well-educated, either". (Participant 6, L 277, 278)*

*"And I cannot say 100% of sicklers are coming because they are sick. Some are addicted". (Participant 1, L 349, 350)*

*“Because they know the timings. They will memorize the timings of the medications, rather than the nurse ..... So, we will say, “See, he is addicted. Even with morphine, he would not be satisfied”. (Participant 2, L 130, 134)*

## **Summary**

Three themes had been found after analysing the data which were: nurses’ experiences of caring for patients with pain associated with SCD, nurses’ attitude towards patients with SCD during painful crisis and participants’ CS and CF associated with managing patients with SCD crises.

Nurses were expert in treating patients with SCD during painful episodes, but they felt it a challenge to perform such a task. Nurses shared their experience with assessing and managing pain, the routine pharmacological management and the non-pharmacological measures. Then, participants shared some difficulties they faced during their professional career such as: difficulty in accessing IV line, which was the most common cause, patients’ behaviour, lack of knowledge about the disease, continual complaining from the patient, while language was the least presented factor. There was a common thought among participants that not all patients with SCD had real pain when seeking hospital care. Some nurses believed that giving narcotic drugs intravenously in the ED leads to addiction among patients. The thought of drug addiction among SCD was noticed throughout by most of the participants.

In relation to CS and CF, participants showed average to high level of CS, low to average level of CF. BO subscale participants showed elevated in the score of STS that 70 % of them had an average level of STS. The similarities between the current study and previously published work, the differences and what this study add to the published work will be discussed and explained in the next chapter.

## **CHAPTER FIVE: DISCUSSION AND CONCLUSION**

This study aimed to answer the inquiry about nurses' experiences, feelings, beliefs and thoughts while caring for patients in pain secondary to SCD and to measure the effectiveness of this care on registered nurses CS, BO and STS levels throughout the care especially in the critical areas ED, IBDC and ICU. This chapter discusses the findings of this study in relation to experiences of the nurses caring for patients with pain associated with SCD, and the implications for clinical practice.

### **Findings Related to the Research Question**

#### **Registered Nurses' Experiences with SCD Patients**

In the previous chapter three key results in relation to the knowledge, experiences and attitudes of nurses while caring for sickle cell disease patients during crises were reported. In addition, the participants' levels of CS and CF were identified.

The results revealed that all the nurses were experienced in looking after patients with SCD. Consequently, they were able to share their experiences, feelings, beliefs and thoughts about caring for patients with SCD. The participants described aspects of extreme cases for instance, children crying and described how this affected their feelings. Yet, the practicality of looking after patients with SCD emerged as a dominant focus in relation to what the participants raised in conversation about their experiences. For instance, the nurses moved very quickly in to issues about pain presentations and pain management.

Participants also discussed the actual existence of protocols and the need to have clearer protocols; they talked about the need for role clarification in trying to determine patients' pain management. An absence of clear care strategies for pain management came up in the nurses' conversation about their experiences. What appears notable in these nurses' experiences is a pragmatic consideration that the nurses when working with SCD patients is to try and gain control of managing pain symptoms. Reviewing the literature that was reported in chapter two, very few of the studies reported this kind of orientation in relation to nurses' attitudes. This might be because previous studies Glassberg et al. (2013); Pack-Mabien et al. (2001); Porter et al. (2012); and Ratanawongsa et al. (2009) were quantitative and assessed nurses' attitudes based on the different scales and determining the relationships between variables.

This may be a feature of the context of Saudi Arabia and how medical protocols and medical-nursing relationships work with pain management. This need to have a sense of control may also be a result from the nurses' misunderstanding of the disease as well as underestimating patients' pain and feelings. As Veronica and Ellis (2000) found, nurses changed their behaviour and improved their attitude while caring for patients with SCD after understanding the psychological changes that those patients are going through throughout their life particularly during painful crisis.

All participants talked about regimes, the importance of the pharmacological and non-pharmacological pain interventions. The results revealed that nurses in this study used and valued both pharmacological and non-pharmacological interventions for those patients. However, some participants found providing psychological support demanding. This might be an indication that such support exceeded their skill limits and hence the nurses called for the need of professional personnel such as a social worker or a psychological specialist to be part of the management team.

Participants talked freely about the routine work that is done when treating patients with SCD in different care settings. One of the interesting findings to emerge was that ED personnel do not believe in administering intravenous (IV) narcotic drugs to those SCD patients due to the fear of patients' addiction. This is contrary to the international pain management protocols (The American and the Canadian respectively) that emphasise on administering IV analgesia when patients are in acute pain episodes particularly in the ED (NHLBI, 2014; National Institute for Health and Clinical Excellence, 2012).

Routine care as well as the common difficulties e.g. difficulty accessing IV cannulation, they faced during caring for those patients were discussed in detail during the interviews. Some participants shared difficulties particularly regarding staff's ability to tolerate the criticality of the patients. While other participants referred to the difficulty of patient's behaviour whom continue to complain of pain. This does not appear to have been previously reported on and may warrant further investigations with a larger cohort of participants.

When the participants talked about their experience of managing pain in patients with SCD crisis, several participants drew to attention the importance of being competent in managing the situation. They shared issues of cultural significance, things they believed and things they had seen other patients share elements of and how they coped with or continued complaints. The nurses describe their tolerance level in such situations and their ability to either cope with the current situation or not. This aspect of the findings, hinted at some of the issues these participants faced in their daily life while caring

for those patients and highlights possible connection to the ongoing attitudes or to their experience to compassion satisfaction and compassion fatigue.

### **Participants' Attitudes Towards Patients with SCD**

Nurses' attitudes that emerged from the participants' answers fell into three categories: their feelings while caring for patients with SCD, doubting the severity of patient pain and drug addiction among SCD. Most of the participants described it as hard work to nurse those patients especially during painful crises. Consequently, the participants shared that they made some adjustments during their care giving to protect themselves from over stress. The most difficult aspect of care was evaluating patients' severity of pain. Participants felt the difficulty in determining the actuality of pain that the patient had. The participants did not talk much about this point this might be due to the sensitivity of this point or it was hard for them to express their feelings. In addition, some nurses shared their coping measures, e.g. treating patients with empathy or adjusting to these situations that they used to adapt with the situation as described in Chapter four.

There was a variation between nurses about their ability to determine the patient's pain. Some nurses spoke confidently that they could tell when a patient had real pain or not, while other nurses were not sure how to evaluate the severity as well as the accuracy of the pain. This variation between nurses could be based on their experiences with such patients or to their pre-impression from certain patients. This is not a new phenomenon for nurses who care for patients with SCD. As identified in the literature review, it has previously been reported that nurses do not believe the patients when they complain of pain (Booker et al., 2006; Haywood et al., 2009).

Even though, this is not a new finding it suggests that perhaps further research is required into nurses' attitudes to pain management in nursing SCD patients because it flows against the goal of care for providing pain management for sickle cell patients, which is to enable their patients to be pain-free. While doubting those patients' pain, it may result in delays in the required care and increase patients' suffering.

Participants faced different types of patients who acted differently not only in relation to their pain, but in the manner they requested attention to be treated. These variations in patients' attitudes and in hospital presentations made participants believe that some patients were drug addicted rather than having real pain and need to be treated effectively. Nurses varied in their view about this issue of possible drug addiction but all of them reported it as an aspect to be minded while treating those

patients. Holding such a view from nurses might make it difficult to build a trustful relationship between patients and nurses and may will be an influence on the management plan. The participants shared some patients' behaviours that caused them to question the reality of the pain that the patient has. For example, the patient's knowledge about his/her medication and its dose along with patients' requests to have the dose on the time prescribed. This behaviour from nurses has previously been hinted in the literature (Booker et al. (2006), Haywood et al. (2009) and Wright & Adeosun (2009). These studies concluded the negative behaviour from health providers in general, was a barrier to effective pain management.

As previously mentioned, the participants shared that ED personnel do not give any SCD patient intravenous analgesia. However, in the context of where this study was undertaken there are several health settings and it is not known if this practice is common across these settings or just pertaining to this hospital. There might be a misunderstanding of the international guidelines for pain management or it might be that the health providers are not following any guidelines.

### **Participants' CS and CF**

As described in Chapter four in relation to CS and CF results, participants' CS ranged between high and average and none of them had a low CS. This was not exactly as the previous research found. In the previous literature nurses tend to show mild to moderate satisfaction (Karanikola et al., 2012; Ozden et al., 2002; Young et al., 2011). Interestingly, Young et al. (2011) research showed ICU nurses to have low CS. While in our study none of the participants scored low; even those who had an average level bordered on high level scores (except for one participant). Our study of course had insufficient numbers to comment, but the finding does raise the need for further research.

Participants expressed their happiness at being nurses and helping others although it is a demanding job. The trend of the participants' scores for the three scales, from answering the ProQOL 5 questionnaires, moved from equal percentage in CS scale between average and high, to slight variation in the BO scale, with forty percent in the low portion of the scale, while sixty percent showed average BO. In contrast, seventy percent of participants were in the average level for STS and thirty percent had low STS. Six out of ten participants showed an average level of BO and seven of them had an average level of STS. There were five participants who had an average level of both subscales, which increases their risk of getting BO with time if still facing the same situation. Although the previous literature used different tools rather than our study, there were some similarities when comparing the final results. ED

and ICU registered nurses showed average to high levels of BO, STS or stress ( Beck, 2011; Karanikola et al., 2012; Ozden et al., 2002; Shoorideh, Ashktorab, Yaghmaei, & Majd, 2015; Young et al., 2011). We found that registered nurses scored moderate to low BO and STS but the increase in numbers of those who had average scores in both scales indicate that they might be at risk of developing higher scores in both negative scales and then this might affect their quality of work as well as their lives. The number of years' experience may have an effect on participants' BO and STS levels. Caution needs to be taken into consideration with these results as the ProQOL 5 was only used as tool to trigger deeper conversations with the participants during their interviews. The numbers are so small the percentages are relatively insignificant. However, this study opens the door for further research in relation to specific conditions especially for the critical nursing departments. HCPs face both primary and secondary stressors in their daily life work. Steam (2010) indicated that STS is mainly concerned with secondary not the primary stressors. Based on the few literatures that examined this subject among nurses in the ED and the ICU, this result may indicate that those nurses are at high risk to have BO and this may affect their life. This may be a result from the work overload, or nurse's feelings of being helpless for their patients.

What was missing in this particular part of the study, was the participants' comments on their scores for the three scales but unfortunately none of the participants wanted to comment on their score. It might be because a time for another interview session needed to be scheduled or it might be because the participants did not want to talk about this issue. To have had the chance to have participants' view about what they think regarding their scores, might have provided an explanation for this variation in the scores. When the nurses were answering the questions, it was observed that there were several phrases that were difficult for them to follow up and to determine what the question was asking. Some phrases had to be translated into Arabic so they could answer the questions. The tool has not been officially translated to Arabic and not been tested for the validity or the reliability. Further research needs to be undertaken in relation to this phenomenon from different settings and amongst a wide range of registered nurses.

From the discussion with those participants, some shared their intentions to leave their professional because of some patients' behaviours. One of the participants 'off the record' shared her personal experience of losing a member of her family due to SCD and how she changed her placement due to this event. She tried to avoid caring for those patients because they reminded her of her relative.

Thinking and recalling patients' different conditions and outcomes seems to have an effect on nurses' personal and professional lives. Some participants recalled conditions that happened from years ago but

they could recall each moment of it as it happens in the present. They had to get comfort and support from their families rather than seeking a professional consultation to help them go through this situation.

The findings of this study supports the previous research related to nurses CS and CF in the critical departments as explained in chapter two. In the previous researches, several tools had been used to measure nurses' CS, CF, BO and stress. Only two studies had used the same tools that have been used in this research (Hunsaker et al., 2015; Young et al., 2011). The results from both studies were similar to the findings from this study about the distribution of nurses' levels in the three scales.

### **Limitations**

The limitations of this study are mainly in relation to the nature of qualitative research, the sample size and recruitment, the setting, and researcher's experience and skills in interviewing. Qualitative research such as the methodology used in this study, qualitative description carried limitations in the scope, scale and transferability of the study.

One of the limitations is the setting, the study drew data from only one hospital that cares for patients with SCD, where as in the Eastern province there are about 20 medical facilities either governmental or private hospitals which may provide care for those patients. The study findings are limited to information from this one site; other settings may have produced different results. The study drew data over one month from three units in one hospital, through the voices of 10 participants who were interviewed once. This does not mean it is representative of other nurses' experiences working in the three units or across the hospital.

A second limitation was the sample of participants who provided the data for the study. The sample size was relatively small ( $n=10$ ), and drawn from predominately ICU nurses due to the limited participatory uptake by ED and IBDC based nurses. Different nurses from different work areas may have resulted in similar or different findings. Caring for patients with a SCD crisis in the general wards may be different to caring for patients in ED, IBDC or ICU.

An individual semi-structured interview was used to collect the data and a novice researcher used the method. A more experience researcher may have elicited different data from the participants.

## **Implications and Recommendations**

This study provides data to describe nurses' experiences, their attitude, their CS and CF while caring for patients with SCD during painful crisis. The implications and recommendations from this study will be discussed in relation to:

- Future research
- Pain management courses for registered nurses in different care facilities.
- Creating a program for registered nurses to be specialized in SCD and its management.
- Including a whole subject in nursing university about SCD and pain management in particularly.

### **Future Studies**

The literature review provided few researches that investigate nurses' attitude or HCPs towards patients with SCD. The few studies had been found were mainly conducted in the western countries and none of the studies examine nurses in Saudi Arabia. A replication for the current study with larger sample size and in different settings is required to explore nurses' experience and believes while caring for patients with SCD. Further researches in the Middle East countries and in Saudi Arabia in particularly are needed especially in the regions where the disease mainly occurs. Nurses should be included in the research process to identify the areas for improvement where research can take place. Further researches should include patients' perceptions about the delivered care as well as the medical team.

Another area for improvement, which needs further studies, is the evidence for pain management as well identifying nurses' role during painful crisis management. As indicated by one of the participants that performing a written protocol for nurses as guidance is important for patients and nurses, especially the new registered nurses who have not cared for those patients before.

Another aspect for research area may include verifying and validating pain assessment tools that have been used in the hospitals for assessing patients' pain. To our knowledge no studies have been done in this sector specifically for patients with SCD. Nurses are using these tools and their treatments depend on them but without validation to their effectiveness in assessing patients' intensity of pain.

### **Education**

Based on the literature as well as from our study we found that nurses lack the adequate knowledge to care for SCD patients. It is one of the difficult conditions that nurses face in their work and in order to

provide maximum care for those patients, nurses must understand the nature of the disease, know the physiology of pain, and differentiate between an acute painful crises as well the chronic one. Nurses are required also to be able to assess and manage their patients correctly and proceed with the evidence-based practice.

Education should be considered from three different aspects. Community and patients' education about the nature of the disease, the methods where people can reduce the prevalence of the disease by taking genetic pre marriage test for example. Instructing patients about how to take care of themselves, and how to avoid certain triggers that may influence their pain. In addition, nurses need to understand the nature of SCD as well as the painful crisis that patients have. A subject about SCD and pain management should be included in the university curriculum and courses about pain management, adequate pain assessment tools which could influence nurses' positive attitude towards patients with SCD. This might help build a trustful and good relationship between patients and nurses.

## **Conclusion**

Nurses' attitudes toward patients with SCD had been mainly studied through quantitative designs. This is the first qualitative descriptive research to explore nurses' experiences and thoughts in relation to this topic. Moreover, the few studies that examined nurses' attitudes toward patients with SCD and had been conducted either in USA or the UK. Thus it would appear that this is the first study to be conducted in Saudi Arabia concerning nurses' attitudes and their experience while caring for patients with SCD in a painful crisis. Despite being country specific there were similar findings to the previous research along with some variations in the results.

In particular in relation to nurses' attitude toward those patients similarity was from two aspects. Firstly, nurses found it difficult to determine the severity of patients' pain, which could lead to doubting the reality of pain occurrence and result in not believing patients when they complain of pain. Secondly, nurses had a general believed in the occurrence of drug addiction among patients with SCD, which was mainly noticed when the patients were seeking medical care. One of the interesting findings was the local practice protocol that they followed when treating patients in the ED, which recommended that IV analgesia for patients not be administered because it leads to addiction.

In this study, the nurses' self-score levels of CS and CF associated with treating patients with SCD were explored. Participants generally showed equal distribution between average and high levels of CS. Regarding CF nurses varied between average to low in both sub scales, which are the BO and STS. The

most noticeable result was that most of the participants were in the average level of both subscales. Additionally, five of the participants showed an average level on both scales, which increase their risk of CF.

This is the first global study that combines the degree of CS and CF among nurses' while caring for those patients and offers a springboard for further research in this field to be undertaken.

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# APPENDICES

## Appendix 1 Search Strategy Tables

Appendix 1a. Database Search Results regarding SCD and Nurses' Attitude

Data bases	1- attitude of health personnel	2-SCD	3-pain management	4-ED	5-ICU*	6-IBDC	1&2 &3&4	1&2 &3&5	1&2 &3	2&3 &5	2&3 &6
CINAHL	27,664	(2,095	13,578	22,819	20,020	1,604	0	0	5	0	2
Pub Med	124648	18269	18482	52262	58993	0	1	0	7	0	0
SCOPUS	112,951	11,854	16,932	11,577	109,224	338	0	0	5	2	2
Ovid MEDLINE	95463	9514	27903	42054	91819	0	0	0	12	1	0
Reviewed							1	0	29	3	4
For critical review							0	0	12	1	2

Appendix 1b. Data bases searching strategy regarding CS, CF, BO, and STS in both departments ED, IBDC and ICU.

Data bases	1-CS	2-CF	3-BO	4-ST5	5-ED	6-ICU	7-IBDC(centre)	8-IBDC(center)
CINAHL	85	337	6,322	135	22,819	20,020	1,604	1,612
Pub Med	257	97	9,689	7,700	52271	120,293	Mesh= 0 Pub med= 185	Mesh= 0 Pub med= 378
SCOPUS	78	162	5,669	186	11,577	109,224	338	338
Ovid MEDLINE	55	251	8,944	103	42085	56,952	0	0

(Combination of the key words through the search process)

Data bases	1 OR 2 OR 3 OR 4 AND 5	1 OR 2 OR 3 OR 4 AND 6	1 OR 2 OR 3 OR 4 AND 7	1 OR 2 OR 3 OR 4 AND 8	Articles to be reviewed after removing duplicates and unrelated articles
CINAHL	38	49	0	0	5
Pub Med	4	10	0	0	6
SCOPUS	14	32	0	0	8
Ovid MEDLINE	19	49	0	0	20

Appendix 1c. PICO identification for the research question

P	Registered nurses caring for patients with pain secondary to SCD in ED, IBDC or ICU.	I	Registered nurses' experiences and attitudes towards patient and its effect on them personally.
C		O	Effective pain management and identifying the level of CS, CF, BO and STS among ED, IBDC and ICU registered nurses.

## Appendix 2 Critical Review of Included papers: Sickle Cell Disease and Pain Crises (IBDC/ED/ICU) –

### Authors A-Z

Booker, M. J., Blethyn, K. L., Wright, C. J., & Greenfield, S. M. (2006). Pain management in sickle cell disease. *Chronic Illness*, 2, 39–50. doi:10.1179/174592006X93860

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 2, medicine, UK. Author 2 H index 2, national health service, UK. Author 3 H index 26. Author 4 H index 23. University of Birmingham, medical school (1, 2). Sickle cell and thalassemia centre, city hospital (3). University of Birmingham, primary care (4).	Chronic Illness, 2006 (Peer reviewed journal). SJR: 0.812, IPP: 1.917, SNIP: 1.048.	Country- Birmingham, UK. Setting; sickle cell and thalassemia centre at city hospital, Birmingham.	Patients dingoed with SCD and experienced painful crisis at least one time.	Primary research.

#### Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Qualitative design. <i>Research aim:</i> To explore participants' experience and views of pain management, access to treatment and relationship with health professionals.	<i>Sample size:</i> 10 patients with SCD. <i>DC:</i> focus- group interview. <i>DA:</i> thematic analysis. Three coding: open coding, axial coding to group related issues and final selective coding.	3 Themes: fear, coping and interaction with others. <i>Conclusion:</i> patients have to convince doctors that they are in pain. Avoiding consultation due to disbelieve behaviour from health professionals. Many doctors do not have the knowledge to treat SCD.	CASP assessment tool for qualitative research. Outcome: 8/10. The lack has been noted in the analysis part which was not sufficiently explained. Included.	Relevant.

#### Data Extraction

Health care providers' attitudes (patients' perspective)*	Barriers to effective pain management (patients' perspective)*
Patients felt being disbelieved by HCPs. Not trusting patients.	Lack of knowledge about SCD.

Glassberg, J. A., Tanab, P., Chow, A., Harper, K., Haywood Jr, C., DeBaun, M. R. & Richardson, L.D. (2013). Emergency provider analgesic practices and attitudes toward patients with sickle cell disease. *Annals of Emergency Medicine*, 62(4), 293-302. doi:10.1016/j.annemergmed.2013.02.004

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 5, emergency medicine. Author 2 H index 17, nursing. Author 7 H index 17, emergency medicine. Icahn School of Medicine (1 & 7), University of New Mexico, Department of Emergency Medicine (2).	Annals of Emergency Medicine, 2013. Impact factor 4.333 Rank Q1; 1/25	<i>Country:</i> USA. <i>Context:</i> Different as the focus was on all healthcare providers.	Health care providers (Attending physicians, nurse practitioners, medical students, residents, physician assistants, others) who work in the emergency department. Setting: Emergency Department.	Primary research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Cross-sectional survey. <i>Research question</i> What are the factors for self-reported non-adherence to the national guide lines for vaso-occlusive pain management in SCD patients?	Sample size: 671 completed surveys. DC: Self-administering survey. DA: descriptive statistic for demographic, practice pattern and attitude scale by presenting medians and interquartile range. 't' test and x2 used to present comparison means and proportions. P<.05 was factor analysis significance value.	67% of respondents are academics. <i>Providers' positive attitude:</i> Attending Ref, nurses=-0.5 (-8.0 to 5.3), white 14.3 (5.8 to 20.6), black 0.9 (-4.2 to 5.5), primary adult -7.6(-11.5 to -3.6), primary paediatric 11.0 (-2.4 to 19.8). <i>Providers' negative attitude:</i> Attending Ref, nurses 4.0 (-3.2to9.6), white -7.9 (-16.0 to -1.8), black 6.3 (1.4 to 10.7), primary adult 6.6 (2.9 to 10.5), primary paediatric -16.5 (-29.3 to -8.0). Pain management: 95% Administering Morphine. 91% administering Hydromorphin. More than 90% used parenteral doses. 85% re-dosing opioids after 30 minutes. 95.1% avoiding Meperidine. 19.7% chose subcutaneous route over intramuscular one. Using PCA in paediatric 6.6 (2.6 to 16.6), adults 1.5(0.8 to 2.7).	By using the CASP assessment tool in relation to cohort study. Outcome: 9/12. Since it is a cross-sectional so the item related to following up and time is not applicable. Majority of participants are academic which may indicate information bias. Included.	Relevant.

Data Extraction

Health care workers (HCWs) attitudes	Pain management in ED	Barriers to effective pain management
Factors affecting HCWs' attitude for treating pain. Patients' age. Number of treated patients. Providers' race.	Pain management protocol: Administering analgesia "Morphine & Hydromorphine". Re dosing frequency and intervals. Routs of administration. IVF therapy 'dehydration'. Adults' providers use PCA less frequently than paediatric ones.	Negative HCWs attitude. Analgesia practice was affected by providers' attitude. Providers with negative attitude were less likely to administer analgesia after 30 minutes.

Haywood, C., Beach, M. C., Lanzkron, S., Strouse, J. J., Wilson, R., Park, H., . . . Segal, J. (2009). A systematic review of barriers and interventions to improve appropriate use of therapies for sickle cell disease. *Journal of the National Medical Association, 101*(10), 1022-1033. Retrieved from <http://search.proquest.com/docview/214047027?accountid=12528>

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 14, medicine and nursing. Author 2 H index 25, medicine and nursing. Author 8 H index 34, medicine. Johns Hopkins University (1 & 2 & 8).	Journal of the National Medical Association, 2009. Impact factor 0.858. Rank Q3; 98/156.	Country- USA. The included studies were from patients' perception as well as providers' perception.	Patients with SCD, nurses and physicians treating those patients. 38 studies about all interventions but 13 only about pain management.	Secondary source.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Systematic review. <i>Research question</i> What are the barriers to use the recommended therapies for patients with SCD? Are the available therapies effective in treating patients with SCD?	Sample size: 48 studies related to pain management (qualitative, quantitative and mixed methods). DC: searching through scientific databases through 2007. DA: synthesis analysis for the extracted data. They were presented in detailed evidence and summary tables.	Relevant Themes: barriers to use of recommended therapies among patients with SCD. Interventions to improve use of recommended therapies for SCD patients. Conclusion: pain management is the most studied therapy. The 2 most barriers were negative providers' attitude and providers' lack of knowledge.	SR quality assessment tool from CASP was used to assess the quality of the paper. Outcome: 8/10 scores. I am not sure if all the relevant studies have been included. Some studies found dated in 1999 but they were not included in this review. Included.	Strongly relevant.

Data Extraction

Pain management for SCD in ED	Health care workers' (HCWs) attitudes	Barriers to effective pain management
No proper medical care in ED (long time for admission, felling forgotten). Difficulty in relating to health care team (poor communication, not being believed). Providers lack of knowledge.	Patients' perceptions: Nurses do not trust patients in relation to treat their pain. Being treated with suspicion and mistrust. Working hard to convince doctors about their pain. Avoiding ED visit not to face disbelieve attitude. Mistrust, neglect, stigmatization and lack of control were reported as patients' experiences with care. Health care providers' perception: Fear of drug addiction or overdosing. Not believing patients report about pain scale.	Negative providers' attitude. Poor provider knowledge about the disease and its management. Inadequate pain assessment tools. Lack of psychological support. Narrow range of available analgesia. Lack of experience with SCD patients.

Labbe, E., Herbert, D., & Haynes, J. (2005). Physicians' attitude and practices in sickle cell disease pain management. *Journal of Palliative Care*, 21(4), 246–251. Retrieved from <http://search.proquest.com/docview/214198506?accountid=12528>

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 14, psychology, and medicine. Author 2 H index 11, psychology. Author 4 H index 20, genetics. University of South Alabama, comprehensive sickle cell centre.	Journal of Palliative Care, 2005. Not peer reviewed journal. Impact factor 0.679. Rank Q4; 81/ 89.	Country- USA, Alabama. Setting; 7 national institutes of health-funded university-based comprehensive sickle cell centre.	Primary care residents, primary care faculty, haematology fellows and haematologists.	Cross-sectional research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Cross-sectional. <i>Research question</i> What is physicians' attitude and practice in the management of painful episodes in patients with SCD? Is there a correlation between physicians' attitude towards addiction and the reported pain management practice?	<i>Sample size:</i> 109 out of 286. <i>DC:</i> physicians' attitude survey (29 items). <i>DA:</i> Spearman rank-order correlation. Pearson product-moment correlation.		CASP assessment tool for cohort studies has been used. <i>Outcome: excluded</i> <i>Not matching the including criteria.</i>	

Data Extraction

Physicians' attitudes only presented, no nurses were involved in the study.
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National Heart, Lung and Blood Institute, (2014). *Evidenced- based management of sickle cell disease: expert panel report*. Retrieved from <http://www.nhlbi.nih.gov/health- pro/guidelines/sickle-cell-disease-guidelines>

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index NA. Author 2 H index NA. Key Affiliation: NA.	2014.	USA.		Evidence report.

Research Summary

Key chapters	Main findings for vaso-occlusive crisis	Topic Relevance
Introduction and methodology Health maintenance for people with SCD. Managing acute complications of SCD. Vaso-occlusive crisis. Managing chronic complications of SCD. Hydroxyurea therapy in SCD. Blood transfusion in SCD.	Assess patients’ pain symptoms, location, and intensity of pain based on patient self-report and observation. Obtain analgesia history from patients. Analgesic therapy within 30 minutes of triage or within 60 minutes of registration. Base analgesic selection on pain assessment, associated symptoms, outpatient analgesic use, patient’ knowledge of effective agents and doses, and past experience with side effects. Mild to moderate pain relief with NSAIDS. Severe pain, treated with parenteral opioids (IV or subcutaneous). Administer parenteral opioids using the subcutaneous route when intravenous access is difficult. Reassess pain and re-administer opioids if necessary for continued severe pain every 15–30 minutes until pain is under control per patient report. Initiate patient-controlled analgesia (PCA) around-the-clock when applicable for children and adults. Included.	Relevant.

Data Extraction

Pain management in ED	Health care workers (HCWs) attitudes
Acute pain management recommendations based on drugs, doses, route of administration, pain assessment, involving patients in care. Analgesia should be administered within 15-20 minutes from assessment or 30 minutes from registration.	Involving patients in the care.

Pack-Mabien, A., Labbe, E., Herbert, D., & Haynes Jr, J. (2001). Nurses' attitudes and practices in sickle cell pain management. *Applied Nursing Research, 14*(4), 187-192. doi:http://dx.doi.org/10.1053/apnr.2001.26783

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 3, medicine, and nursing. Author 2 H index 14, psychology, and medicine. Author 4 H index 20, genetics. University of South Alabama, comprehensive sickle cell centre.	Applied Nursing Research, 2001. Not peer reviewed journal. Impact factor 0.733. Rank Q3; 76/ 110.	Country- USA, Alabama. Setting: a southern university teaching hospital. ED and medical-surgical units.	Student nurses, licensed practical nurses, registered nurses, advanced practice nurses, and adult and paediatric health nurses.	Cross-sectional research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Cross-sectional. <i>Research question</i> What is the influence of nurses' attitude on their practice when caring for patients with SCD during painful episodes? What is the influence of nurses' age, education, experiences and area of practice on their attitudes and practice in sickle cell pain management?	<i>Sample size:</i> 77 were completed out of 200 over 4 weeks. <i>DC:</i> a developed survey contains 31 items, <i>DA:</i> Somer's D and Spearman rank-order correlation.	Participants' age 41% between 20- 29 and 31% between 30- 39. 70% of participants have < 10 years' experience 63% believed patients were addicted. 49% of them have 0 to 5 years' experience. 97% believed addicted SCD patients have painful episodes. 87% believed not to consider addiction as primary nurses concern. 49% of participants reported lack of knowledge about SCD. Concern about addiction Decreased as nurses' age increase (D= -0.0931, P= 0.564). Decreased as experience increase (D= -0.1308, P= <.01). Decreased as level of education increase (D= -0.16, P= <0.01). 62% experience frustration when caring for patients with SCD. <i>Barriers to effective pain management:</i> Drug addiction as barrier: 50% did not agree, 30 % agree and 17% did not know. 58% lack of time for psychological support. 37% nurses reluctance to give opioids. 37% narrow range of available analgesia. 33% physicians' reluctance to prescribe opioids. 32% SCD are drug addicted. 27% excessive state regulation for analgesia. 16% patients refuse to take opioids. 10% patients' hesitance to report pain. 61% of respondents report inadequate pain assessment tools.	CASP assessment tool for cohort studies has been used. <i>Outcome:</i> 8/12.  Included.	Relevant.

Data Extraction

Health care providers' attitudes	Barriers to effective pain management
Patients with SCD are drug addicted. Nurses' age, experience and education level influences their attitude towards patients with SCD during painful crisis. Patient's addiction is not a primary concern in the management.	Patient as drug addict. Lack of knowledge about SCD. Hesitant from analgesia prescription (physicians), giving (nurses), or patients refuse the dose or not reporting pain when occur. State regulations and limited available opioids (medication). Categorizing patients as drug addicted.

Porter, J., Feinglass, J., Artz, N., Hafner, J., & Tanabe, P. (2012). Sick cell disease patients' perceptions of emergency department pain management. *Journal of the National Medical Association, 104*(9-10), 449-454. doi:10.1053/apnr.2001.26783

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 6, medicine, psychology USA. Author 2 H index 41, medicine, nursing USA. Author 5 H index 17, nursing, Medicine, USA. St. Jude Children's Research Hospital (1), North western University Feinberg School of Medicine (2), University of New Mexico, Emergency (5).	Journal of the National Medical Association, 2012. Impact factor 0.858. Rank Q3; 98/ 156.	Country- USA. Context: it concerns patients' perspective rather than the nurses which is different from the scope of our project.	Patients with pain secondary to SCD in the ED. Setting: 3 x different EDs (2urban, 1 rural).	Original research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Prospective, longitudinal cohort study. <i>Research question</i> How do patients evaluate their pain management in the ED? What is the effect of patients, providers, or interpersonal factors on patients' ratings of their pain management in the ED?	Sample size: 209 interviews with 98 patients, total of 1842 ED visit. DC: systematic medical record data extracted followed by interviewing patients after 7- 14 days after discharge. DA: Results have been presented by medians and IQRs for Slewed distribution. Univariate analysis. X2 test of association for categorical variables.	Median participants' age 33Y (24- 41). Number of ED visits 22 (7.5- 74). Median of analgesia doses 3.0 (3.0- 4.0). Inadequate pain management in sites 1, 2, 3 respectively (50%, 73%, 82%). Good pain management in sites 1, 2, 3 respectively (50%, 27%, 18%). Treated with trust and respect Triage nurse 86% ED nurse 86% ED physician 83%. Analgesia administration median 77.5 (51.0- 142.0).	CASP assessment tool for cohort studies. Outcome: fair quality, 8/12. It might include informational bias. Patients' interviews were conducted 7 to 14 days after initial visit which may not be accurate. In relation to providers' attitude, it does not fit with the previous research. It may be improved but still needs further research. All 3 sites are included in quality improvement program for pain management Included.	Relevant.

Data Extraction

Health care providers' attitude	Barriers to effective pain management
Patients were treated with respect and trust by triage nurses, ED nurses and ED physicians.	Patients indicated that their pain management was not adequate and they were not satisfied with the pain.

Ratanawongsa, N., Haywood Jr., C., Bediako, S. M., Lattimer, L., Lanzkron, S., Hill, P. M., . . . Beach, M. C. (2009). Health care provider attitudes toward patients with acute vaso-occlusive crisis due to sickle cell disease: development of a scale. *Patient Education and Counselling*, 76, 272-278. doi:10.1016/j.pec.2009.01.007

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 13, medicine & nursing. Author 2 H index 14, medicine, and nursing. Author 8 H index 28, medicine and nursing. Key Affiliation: University of California (1), Johns Hopkins university (2 & 8).	Patient Education and Counselling, 2009. Impact factor 2.6. Rank Q1; 39/162.	USA. Context: selected care providers based on patients preference.	Adult patients with SCD and their health care providers (HCPs) (nurses, nurse practitioners, physician assistants, or Physicians providing) ED or in-patients settings.	Research Prove validity of a scale to HCPs attitude towards patients with SCD.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> <i>Cohort I study.</i> <i>Research question</i> What is the correlation between patients and provider level characteristics with positive attitudes towards patients with VOC?	Sample size: 121; 47 patients & 84 HCPs. DC: patients' demographic data collected by interview patients. Patients' medical characteristics collected from medical record. DA: exploratory factor analysis to capture more than one dimension of provider attitudes. Exploratory principal components analyses and scree plots, retaining factors with Eigenvalues greater than 1.	Providers' attitude 12–13% of surveys indicated below average liking, empathy, and respect for their patients. 17% of providers felt frustrated in caring for the patient. In two-thirds of meetings, providers felt manipulated, patient exaggerated discomfort, fail to comply with medical advice; abused Patient's condition was associated with providers' attitude.	It focuses on validating a scale as well as comparing HCP s attitude in 2 different settings. Outcome: 9/12. The inclusion criteria stated clearly but there was payment for patients as a reward for their participation. There was no control group to compare between them since it aims to study certain group of patients with their providers. This study was conducted over nine months with constant follow up for same patients during this period. The result approves the hypothesis of the study. Included.	Strongly relevant.

Data Extraction

Health care workers (HCWs') attitudes
Nurses have more positive attitude compared to other HCPs. In-patients providers have more positive attitude than ED providers. Patients who have high education and were employed providers score high positive attitude. Frequent hospitalization, acute chest syndrome condition and vascular necrosis were associated with negative providers' attitude. Patients' previous bad behaviour toward staff was significantly associated with low providers' positive attitude scale.

Tanabe, P., Myers, R., Zosel, A., Brice, J., Ansari, A. H., Evans, J., . . . Paice, J. A. (2007). Emergency department management of acute pain episodes in sickle cell disease. *Academic Emergency Medicine*, 14(5), 419-425. doi:10.1111/j.1553-2712.2007.tb01801.x

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 17, nursing, medicine, USA. Author 2 H index 2, medicine USA. Author 9 H index 33, medicine, nursing, USA. Duke University (1), University of New Mexico, Department of Emergency Medicine (2), North western University Feinberg (9).	Academic Emergency Medicine, 2007. Impact factor 2.198. Rank Q1; 26/25.	Country- USA. Context: target group are patients are different from population targeted in the project.	Adult patients with acute episodes of pain secondary to SCD. Setting: 3 x academic medical.	Original research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Retrospective study <i>Research question</i> What are the ED protocols when managing pain are they march with American Pain Association protocol, and what causes the delay in giving the initial dose of the analgesia?	Sample size: 529 patients' visits were included. DC: structured medical review from ED medical records DA: descriptive statistics to report and describe the study variables. Means and 95% confidence intervals between groups was reported.	Median time to administer initial dose is 90 minutes (54- 149). Time from arrival to be placed in a room take average 59minutes. 87% of total visit, patients received either morphine or hydromorphone. 92% received the recommended dose, 55% receive it either IV or SQ. Factors associated with longer time to administer analgesia: Gender, female 125 +/- SD 89 while male 103+/- SD 80. Mean difference 21 minutes, 95% CI= 7 TO 36mints Triage category 1 & 2 (82+/- 56) compared to 3 & 4 & 5(127 +/- 91); mean difference 45 mints, 955 CI= 29 TO 61 MINTS Patients who do not have IV access waited longer (mean 132 +/- SD 89 minutes) compared to patients with IV access (mean 107+/- SD 83) mean difference 24 mints, 95% CI= 8 to 40 mints.	CASP assessment tool for cohort study. Outcome: 8/12. Clear aim and focus population. Patients' records retrieved from hospitals system according to including criteria. Presented data have been validated by presenting the mean, standard deviation, 95% confidence interval for each variable. Inter-rater reliability has been conducted and explained. The included data from 3 different settings and over a year. The result fits with previous studies has been conducted. The study design, it can be an observational. Included.	Relevant.

Data Extraction

Pain management in ED
Patients waited long time before getting their initial dose of analgesia. Morphine or hydromorphone are being used the most. Most patients receive the recommended dose. Half of patients receive the dose either IV or SQ. Factors associated with delay analgesia administration are patients' gender, triage category score, and availability of IV access.

Wright, K., & Adeosun, O. (2009). Barriers to effective pain management in sickle cell disease. *British Journal of Nursing*, 18(3), 158-161.  
doi:10.12968/bjon.2009.18.3.39043

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 11, medicine and nursing. Author 2 H index 1, University of Greenwich.	British Journal of Nursing, 2009. SJR: 0.332. IPP: 0.615. SNIP: 0.519.	UK. The prevalence of SCD is high.	Researches that identify pain management barriers in SCD for adult patients.	Literature review.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> <i>Literature review (narrative)</i> <i>Research question</i> <i>What are the available management for SCD and their effective?</i>	Sample size: not applicable DC: searching data bases. DA: was not explained. Synthesis data analysis.	The manifestation of vaso-occlusive pain Difference of adversity, pain location, severity, pain pattern, and length of description affects quality of pain management. The socio-cultural factors affecting pain assessment Class, race, ethnicity, language may affect negatively patient-provider relationship. The concerns regarding addiction and pseudo-addiction. Providers hastate to prescribe analgesia. Patients request for analgesia translated by providers as drug addiction. Patients may demonstrate pseudo- addiction behaviour to get their pain relive.	CASP assessment tool for SR was used. Outcome: 6/10. There was insufficient explanation for the methodological part. Included.	Relevant.

Data Extraction

Health care workers (HCWs) attitudes	Barriers to effective pain management
Mistrust by health care providers.	Lack of comprehensive assessment to patients. Not listening to patients. Socio-cultural barriers (e.g.) Hesitancy of health-care professionals to administer and prescribe opioids. Lack of knowledge about treating pain.

### Appendix 3 Critical Review of Included Papers: CS, CF (BO, STS) – Authors A-Z

Adriaenssens, J., Gucht, V. D., Doef, M. V., & Maes, S. (2011). Exploring the burden of emergency care: predictors of stress-health outcomes in emergency nurses. *Journal of Advanced Nursing*, 67(6), 1317–1328. doi:10.1111/j.1365-2648.2010.05599.x

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 2, nursing, and medicine. Author 3 H index 11, psychology. Author 4 H index 25, psychology. Leiden University, the Netherlands.	Journal of Advanced Nursing, 2011. Impact factor 1.74. Rank Q1; 10/110.	Country- Belgium. Setting; 15 emergency departments of Belgian general hospitals.	Registered ED nurses who have contact with patients.	Cross-sectional research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
Research design Cross-sectional Research question What extents do personal characteristics, job characteristics and organizational factors on job satisfaction, turnover intension, work engagement, fatigue and psychosomatic distress in Data Extraction ER-nurses?	<i>Sample size:</i> 254 <i>DC:</i> the Leiden Quality of Work Questionnaire (14 subscale) <i>DA:</i> descriptive statistic (mean, median, standard deviation, skewness and kurtosis). Chi-square, t-tests. Hierarchical regression analysis. P- Value of 0.05 or less.	80% hold ED care certificate. Mean experience 15 years (SD= 8.96). Mean experience in ED 11 years (SD= 7.55). 96.10% of ED staff work shifts and 86% of general nurses work shifts. 63% of ED staff work >32 H/W and 53% of general nurses work >32 H/W. Female staff in ED 55.11% while in general nursing 87%. Job satisfaction: Changing shifts (+ night) (B 0.12).	CASP assessment tool for cohort studies has been used. <i>Outcome:</i> 10/12. Included.	Relevant.

Data extraction

ED nurses CS, BO and STS	Turnover intention	Work engagement
Job satisfaction correlate with working shifts, rewards from organization, authority to make decision, and skills performance. CF associated with work demands, rewards, and resources.	Female and older staff presented low turnover intention.	Nurses feel belong to work as working in different shifts. Having supervisor support and performing required skills perfectly, rewording and good quality of work procedures.

Beck, C. T. (2011). Secondary traumatic stress in nurses: a systematic review. *Archives of Psychiatric Nursing*, 25(1), 1–10. doi:10.1016/j.apnu.2010.05.005

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 36, nursing and	Archives of Psychiatric	USA.	Nurses working in different clinical	Secondary research.

medicine, USA. Key Affiliation: University of Connecticut School of Nursing.	Nursing, 2011. Impact factor 1.0. Rank Q2; 45/107.		areas (sexual assault nurse examiner, oncology, ED, chronic ill children).	Systematic review.
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Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<p><i>Research design</i> <i>Systematic review</i> <i>Research question</i> What studies have been conducted on secondary traumatic stress in nurses in all clinical specialties?</p>	<p>Sample size: 7 studies DC: through searching three data bases with using key word. DA: no explanation for data analysis method.</p>	<p>STS and CF were examined among different traumatic and chronic departments. Nurses show high level of CF and STS. 4 of the 7 studies female participants were 91 to 99%. Two common scales for measuring STS; secondary traumatic stress scale (17 items) and compassion fatigue a revised-scale (30 items).</p>	<p>CASP assessment tool for systematic review was used. Outcome: 7/10. Specific questions were addressed for this review. The searching terms used matches the purpose of the study. The included studies were focus on nurses except 2 studies that involve other participants than nurses but nurses were the majority. It may not be included all the studies because of the limitation for English, and published studies only. It has been conducted by one author without explanation to quality and relevance of the extracted data. Included.</p>	<p>Slightly relevant.</p>

Data Extraction

<p>ED nurses CS, BO and STS</p> <p>One study only in the systematic review was about ED nurses. More than two thirds of the sample were women. Third of the participants have elevated STS symptoms. Avoiding patients, difficulty of sleeping, getting annoyed easily and disturbing thoughts about patients.</p>
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Healy, S., & Tyrrell, M. (2011). Stress in emergency departments: experiences of nurses and doctors. *Emergency Nurse*, 19(4), 31-7. Retrieved from <http://search.proquest.com/docview/878973229?accountid=12528>

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
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Author 1 H index 2, nursing. Author 2H index 3, nursing. 1-Mercy university hospital, Cork. 2-Mercy University college, Cork.	Emergency Nurse, 2011. SJR: 0.172 IPP: 0.363 SNIP: 0.337.	Country- Ireland. Context: different health care service than Saudi Arabia.	ED health care personnel. Setting: 3 different ED in Ireland.	Cross-sectional research.
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Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<p><i>Research design</i> <i>Descriptive-survey design.</i> <i>Research question</i> What is ED nurses and doctors experience of stress in the work place and how they manage or reduce it?</p>	<p><i>Sample size:</i> 103, 90 nurses and 13 doctors. <i>DC:</i> self-administered questionnaire. <i>DA:</i> descriptive analysis (mean, range). Relational statistics by using Mann- Whitney U test. Chi square test.</p>	<p>Mean participants' age 33.4 years. Mean professional experience range 11.4 years (1- 35 years). Mean ED experience 5.9 years (3 months– 26 years). 51% frequently experience stress at work. 37% occasionally experience stress. 76% did not receive support to deal with stress while 27% did. <i>Stressful events:</i> 75 work environment, 37 aggregations and violence, 34 deaths or child resuscitation, 30 critical illnesses. <i>Relation between variables and stressors:</i> Age (U= 697, P= 0.012), no. of ED experience (U= 604, P= 0.002), no. of professional experience (U= 663, P= 0.004) AND caring for critically ill patients.</p>	<p>Cohort assessment tool was used from CASP. Outcome: 8/12. This is a report about the study. The result was explained briefly without including tables for detailed outcomes.  Included.</p>	Relevant.

Data Extraction

ED nurses CS, BO and STS (stress among ED staff*)
ED personnel frequently face stressful situations. There is a lack of support for them from management. Participants' age, experiences have an impact on the degree of stress in ED. Work environment is the most stressful event in the ED.

Hunsaker, S., Chen, H., Maughan, D., & Heaston, S. (2015). Factors that influence the development of compassion fatigue, burnout, and compassion satisfaction in Emergency department nurses. *Journal of Nursing Scholarship*, 47 (2), 186–194. doi:10.1111/jnu.12122

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper

Author 1 H index 2, Brigham Young University, college of nursing, Provo, UT, USA. Author 2 H index NA, Department of Nursing, Utah Valley University, Orem, UT, USA Author 4 H index 4, Brigham Young University, college of nursing, Provo, UT, USA	Journal of Nursing Scholarship, 2015. Impact factor 1.77. Rank Q1; 15/107.	Country- USA. Different healthcare context than Saudi Arabia.	Registered nurses who worked in EDs throughout the USA.	Original research.
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Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<p>Research design A cross-sectional, non-experimental, descriptive, study.</p> <p>Research questions 1 What are the prevalence of CS, CF and BO among ED nurses in the USA? 2 What are the demographic and work-related components that may affect the development of CS, CF and BO in ED nurses?</p>	<p>Sample size: 1000 sent, 284 were returned, 278 analysed. DC: ProQOL5 survey packet was mailed to each potential participant. And a remainder mail after 2 and 6 weeks sent. DA: describing CS, CF and BO presented by using means, SD, medians, Pearson r correlation, t test, and ANOVA were used to examine the associations between demographics, work-related characteristics, and the level of CS, CF, and burnout. The <math>\alpha</math> level was set at .05.</p>	<p>87.4% of participants female. 89.2% white. 68.3% married. Mean age 44 years (SD+/- 11.47) Working as nurse mean 17.58 (SD+/- 12.26). Working in ED mean 13.01 (SD+/- 9.89). CS 39.77 (SD= 6.32). CF 21.57 (SD= 5.44). BO 23.66 (SD= 5.87). Higher education certify nurses are more CS (F= 5.48, P=.005) And low BO level (F= 4.92, P=.008). 56% have average CS. Age correlate positively with CS (r=.260, P=.001). Age correlate positively with BO (r= -.134, P= .027). Positive correlation between CS and experience (r= .264, P = .001) and negative correlation with BO (r= -.182, P= .003). 8 to 10 Hs shifts correlate with CS (t= 2.47, P = .014) and low BO (r= -3.34, p= .001).support from managers high CS (t= 3.99, p= .001) and low CF (t= -2.89, p= .005) and low BO (t= - 5.64, p= .001).</p>	<p>Overall assessment score is 10/14 based on the CASP quality assessment tool for observational cohort and cross-sectional study. The participants were 26% only from the eligible sample and there was no explanation about the power description of the sample size. Included.</p>	<p>Relevant.</p>

Data Extraction

<p>ED nurses CS, BO and STS</p> <p>More than half participants show average level of CS, low level of CF and more than half nurses are in the average level of BO. There is a positive correlation between age and CS and BO. Factors influencing CF were age, manger support, working hours per shift and experience. Manager support was negatively correlated with CF and BO level among ED staff.</p>
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Karanikola, M. N., Papathanassoglou, E. D., & Mpouzika, M. (2012). Burnout syndrome indices in Greek intensive care nursing personnel. *Dimensions of Critical Care Nursing*, 31(2), 94–101. doi:10.1097/DCC.0b013e3182445fd2

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
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Author 1 H index 5, nursing and medicine. Author 2 H index 14, medicine and nursing. Author 3 H index 3, nursing, Cyprus.	Dimensions of Critical Care Nursing, 2012. SJR 0.286, IPP 0.767, SNIP 0.479.	Greek.	Registered nurses and assistant nurses working in the ICU. Setting: 5 public and 3 private hospitals.	Primary study.
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Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<p><i>Research design</i> Descriptive correlation, cross-sectional survey <i>Research question</i> 1-What is the level of personalization, emotional exhaustion, perception of professional accomplishments and professional satisfaction among Greek ICU nurses? 2- What is the association between BO parameters, professional satisfaction and demographic, vocational and educational factors?</p>	<p>Sample size: 152 participants DC: self-reported questionnaire consists of demographic data, Maslach Burnout Inventory and Index of Work Satisfaction. DA: mean, medians and parametric comparison were used. Logistic regression analysis was performed with log-transformed variables. Parametric correlation coefficient Pearson (r) calculated.</p>	<p>Mean age was 31.8 (SD, 5.4) years. Mean work experience in nursing was 7.3 (SD, 5.8) years. Their work experience in the ICU was 5.0(SD, 4.1)years Mean working weekends was 2.6. DPS mean value of 9.3 (SD, 6.2). EE mean value of 23.8 (SD, 10.2). Perception of professional accomplishments with mean value of 33.8 (SD, 9.0). Professional satisfaction with mean value of 3.56 (SD, 0.56). Private hospitals' respondents have high levels of perceived professional accomplishments (P = .006), low levels of EE (P = .004), and a tendency toward less DPS (P = .073) compared to public hospitals. Private hospitals reported statistically significantly higher levels of professional satisfaction (P = .046). Staff nurses exhibited higher levels of emotional exhaustion (P = .024). Experience in nursing correlated inversely with depersonalization scores (r = -0.214, P &lt;.011). Statistically significant inverse correlation was noted only with the number of weekends worked per month and job satisfaction (r = -0.288, P &lt; .0001).</p>	<p>All over assessment is 8/14 based on CASP quality assessment tool for observational cohort and cross-sectional studies. Where 3 questions are not applicable to cross-sectional studies. Good quality. Included.</p>	<p>Relevant.</p>

Data Extraction

ICU nurses CS, BO and STS
ICU nurses have moderate job satisfaction, moderate closely to high to depersonalization subscale, moderate emotional exhaustion and low professional accomplishment. Nurses working in the private hospitals have more job satisfaction and low BO scores compared to public hospitals nurses. Staff nurses were more prone to BO symptoms compared to nursing managers and assistants. Nurses who have long experience in ICU scored low depersonalization. Nurses tend to be more satisfied with less weekends duty.

Laposa, J. M., Alden, L. E., & Fullerton, L. M. (2003). Work stress and posttraumatic disorder in ED nurses/personnel. *Journal of Emergency Nursing*, 29(1), 23–28. doi:10.1067/men.2003.7

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
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Author 1 H index 10, medicine, psychology. Author 2 H index 26, psychology, medicine. Author 3 H index 2, medicine, nursing. University of Toronto (1). University of British Columbia (2). McGill University Health Centre (3).	Journal of Emergency Nursing, 2003. Impact factor 0.787. Rank Q3; 16/24.	Country: Canada. Context: it involves not only ED nurses. Conducted in an urban area.	ED personnel (nurses, physicians, nursing unit clerks, technicians, housekeeping).	Original research.
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#### Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<i>Research design</i> Cross-sectional survey <i>Research question</i> What is the association between sources of workplace stress and the severity of posttraumatic disorder symptoms?	Sample size: 51 ED workers. DC: Self-administering survey for Health Professional Stress Inventory, Posttraumatic Diagnostic Scale and Work-related Responses to stress or trauma. DA: secondary analysis, measuring mean, standard deviation, analysis of variance and Pearson correlation coefficients.	Average stress score HPSI-R: 57.19 out of 90, (SD= 10.15). Average PSTDS severity symptoms 6.85 (SD= 5.58) severity score range 0- 25. 12% represented full PTSD symptoms and 20% met the criteria for 3 symptoms only. Interpersonal conflict significantly predicted PTSD severity ( $r=.36$ , $P<.01$ ). Interpersonal conflict associated with avoidance ( $r=.32$ , $P<.05$ ) and arousal ( $r=.37$ , $P<.01$ ).	CASP assessment tool for cohort studies was used. Outcome: 8/12. Included.	Relevant.

#### Data Extraction

ED nurses STS	Work stressors
ED personnel showed moderate professional stress, posttraumatic distress symptoms. Individuals have between three symptoms to full symptoms.	Interpersonal conflict between ED personnel.

Ozden, D., Karagozoglu, S., & Yildirim, G. (2002). Intensive care nurses' perception of futility: job satisfaction and burnout dimensions. *Nursing Ethics*, 20(4), 436–447. doi:10.1177/0969733012466002

#### Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
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Author 1 H index NA, nursing, Turkey. Author 2 H index 4, nursing, medicine Turkey. Author 3 H index 3, medicine, nursing, Turkey.	Nursing Ethics, 2002. Impact factor 0.9. Rank Q2; 36/110.	Country- Turkey. Settings: 3 ICUs departments in three different teaching hospitals in turkey.	Registered nurses working in the intensive care units. Setting: 3 x ICUs.	Primary research.
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#### Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance
<p><i>Research design</i> Cross-sectional descriptive study.</p> <p><i>Research question</i> What is ICU nurses' level of job satisfaction and exhaustion? What is the relationship between job satisfaction and BO through the futility dimension?</p>	<p>Sample size: 206 nurses working in the ICU. DC: self-administration (sociodemographic data, the futility questionnaire; Maslach Burnout Inventory (MBI), Minnesota Satisfaction Questionnaire (MSQ) with explanatory statement and consent form. DA: descriptive analysis, The correlation analysis was used to determine the relationship between the total scores of MSQ and MBI. ANOVA) test was used to determine the difference between the items included in all questioners.</p>	<p>Job satisfaction; mean score for job satisfaction was 59.41+14.87. Job satisfaction &amp; personal achievement (r 0.336, p 0.000). Job satisfaction &amp; EE (r -0.416, p 0.000) Job satisfaction &amp; DPS (r -0.324, p 0.000) Job satisfaction &amp; personal accomplishments (r 0.336, p 0.000). Burnout; Undergraduate nurses had statistically significantly high mean scores (p &lt; 0.05) for EE (16.69 + 6.81) and DPS (6.92 + 4.27), and low mean scores for personal achievements (20.05 + 4.66) Experience of &gt;5 years scored (p &lt; 0.05) in relation to personal achievement. Shifting duty was associated with (p &lt; 0.05) high scores for EE (16.73 + 7.05) and DPS (6.88+ 4.31), but low scores for personal achievement (20.25+ 4.79).</p>	<p>A quality assessment tool for observational cohort and cross-sectional studies was used. Outcome: 8/12, good. The justification for sampling was not discussed. The futility questionnaire Cronbach value was 0.6 which is below the acceptable range which may affect reliability and credibility. Included.</p>	Relevant.

#### Data Extraction

<p>ICU nurses CS, BO and STS</p> <p>ICU nurses have moderate job satisfaction. Significant statistical correlation between job satisfaction and emotional exhaustion, Job satisfaction and depersonalization. Positive correlation between job satisfaction and personal accomplishment. No relation has been found between participants' age, marital status, working hours, and number of patients to their job satisfaction or burnout. Education level, number of experience years, shifting (day, night), and ethical training have impact on nurses EE, DPS and personal accomplishment.</p>
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Shoorideh, F. A., Ashktorab, T., Yaghmaei, F., & Majd, H. A. (2015). Relationship between ICU nurses' moral distress with burnout and anticipated turnover. *Nursing Ethics*, 22(1) 64–76. doi:10.1177/0969733014534874

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index NA, nursing, Iran. Author 2 H index 4, medicine and nursing, Iran. Author 3 H index 4, medicine and nursing, Iran. Shahid Beheshti University of Medical Sciences.	Nursing Ethics, 2015. Impact factor 0.9. Rank Q2; 36/110.	Iran. 12 ICU departments.	Nurses working in the intensive care units in academic hospitals in Iran. Setting: 12 academic hospitals.	Original research.

Research Summary

Research Summary	Data collection & analysis	Research findings	Quality Research Assessment	Topic Relevance			
<p><i>Research design</i> descriptive-correlation study, cross-sectional survey</p> <p><i>Research question</i> What is the relationship between moral distress, burnout and anticipated turnover in population of ICU nurses in Iran?</p>	<p>Sample size: 159 Participants. DC: Iranian ICU Nurses' Moral Distress Scale (IMDS), the Copenhagen Burnout Inventory (CBI) and the Anticipated Turnover Scale (ATS) were sent to potential participants with explanation about the survey and return envelope. DA: Correlation analyses and t-tests were applied to examine the correlation. *P&lt;0.05. **p&lt;0.01.</p>	<p>Mean of; Personal burnout was 53.36 +/- SD 20.11. Work-related burnout was 45.55 +/- SD 18.03. Client-related burnout was 44.89 +/- SD 23.07. BO and anticipated turnover p&lt;0.05. Correlation between variables:</p>	<p>A quality assessment tool for observational cohort and cross-sectional studies was used. Outcome: 7/12 It is a good research; it lacks the discussion about statistical power to justify the sampling. Selecting nurses working in academic settings only may trigger bias. Included.</p>	<p>Relevant from the means of burnout among Iranian ICU nurses.</p>			
					personal	Work related	Client related
		Age			0.227	0.158	0.217
		Years' experience			0.215	0.176	0.232
		ICU exp.			0.367	0.319	0.318
N-P rate	0.336	0.232	0.265				

Data Extraction

ICU nurses CS, BO and STS
<p>There was a positive correlation between age, years of nursing experience, years of ICU nursing experience, years of current ICU nursing experience, nurse-to-patient ratio, compulsory overtime work, and the workplace city with burnout. There was no correlation between gender and BO. There was a positive correlation between burnout and anticipated turnover.</p>

Young, J. L., Derr, D. M., Cicchillo, V. J., & Bressler, S. (2011). Compassion satisfaction, burnout, and secondary traumatic stress in heart and vascular nurses. *Critical Care Nursing Quarterly*, 34 (3), 227–34. doi:10.1097/CNQ.0b013e31821c67d5

Author and Journal Credibility, Type of paper

Author Credibility	Journal & year of publication	Context	Population	Type of paper
Author 1 H index 2, medicine, nursing, USA. Author 2 H index NA, nursing, USA.	Critical Care Nursing, 2011. Quarterly. SJR: 0.362 IPP: 0.795 SNIP: 0.538.	USA A specialized heart and vascular centre.	Nurses working with cardiac diseases, cardiothoracic surgery. Setting: 484-bed academic medical centre in central Pennsylvania.	Original research.

Research Summary

Research Summary	Data collection & analysis	Research findings				Quality Research Assessment	Topic Relevance
			CS	BO	STS		
<i>Research design</i> Exploratory descriptive, cross sectional survey <i>Research question</i> What is the difference in prevalence of CS, BO, and STS between heart/vascular nurses working in ICU and intermediate care (IMC)?	Sample size: 68 participants; 25 IMC & 43 ICU. DC: ProQOL 5 instrument. Mailed Survey all nurses in both departments. DA: Spearman coefficient.	ICU	82% average 18% high	36% low 64% average	56% low 44% average	Quality assessment tool for observational cohort and cross-sectional study the quality of the paper was assessed.  Total score of 7/14 with 3 questions are not applicable for cross-sectional studies. Data analysis process was not explained sufficiently in the paper. Included.	Relevant from ICU nurses results.
		IMU	40% average 60% high	84% low 16% average	76% low 24% average		
		The average CS score IMC nurses were 42 and ICU nurses were 37. Average BO score in the IMC was 19 and ICU was 25. The average STS score in the IMC was 19 and the ICU was 22. IMC nurses had 1) higher levels of CS compared with those of ICU nurses (Spearman coefficient= 0.43; P= 0), 2) lower levels of BO (Spearman coefficient= -0.47; P= 0). STS levels between the 2 groups were not statistically significant (Spearman coefficient= -0.20; P= .099).					

Data Extraction

ICU nurses CS, BO and STS
CS score among ICU nurses was between averages to high with majority on average level. BO score among ICU nurses was between low to average with majority on average level. STS score among ICU nurses was between low to average with majority on average level. ICU nurses were less satisfied, average BO score. No significant difference between ICU & IMC for STS.

# Appendix 4 Ethical Approval from Monash University Human Research Ethics Committee



## Human Ethics Certificate of Approval

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

**Project Number:** CF15/111 - 2015000054

**Project Title:** Nurses' attitudes, compassion satisfaction and compassion fatigue associated with the pain management of patients with a sickle cell disease crisis in Saudi Arabia: A qualitative descriptive study

**Chief Investigator:** Assoc Prof Cheryle Moss

**Approved:** From: 5 March 2015 To: 5 March 2020

**Terms of approval - Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.**

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must include your project number.
6. **Amendments to the approved project (including changes in personnel):** Require the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.



Professor Nip Thomson  
Chair, MUHREC

cc: Ms Zahra Ibn Alshaikh

Monash University, Room 111, Chancellery Building 3e  
24 Sports Walk, Clayton Campus, Wellington Rd  
Clayton VIC 3800, Australia  
Telephone: +61 3 9905 5490 Facsimile: +61 3 9905 3831  
Email: [muhrec@monash.edu](mailto:muhrec@monash.edu) <http://intranet.monash.edu.au/researchadmin/human/index.php>  
ABN 12 377 614 012 CRICOS Provider #00008C

## Appendix 5 Ethical Approval from Ministry of Health in Saudi Arabia

Kingdom of Saudi Arabia  
Ministry of Health  
King Fahad Medical City  
(162)

وزارة الصحة  
مدينة الملك فهد الطبية  
King Fahad Medical City

المملكة العربية السعودية  
وزارة الصحة  
مدينة الملك فهد الطبية  
(١٦٢)

IRB Registration Number with KACST, KSA: H-01-R-012  
IRB Registration Number with OHRP/NIH, USA: IRB00008644  
Approval Number Federal Wide Assurance NIH, USA: FWA00018774

April 28, 2015  
IRB Log Number: 15-191E  
Department: External  
Category of Approval: EXEMPT

Dear Zahra Makki Ibn Alshaikh,

I am pleased to inform you that your submission dated April 27, 2015 for the study titled '**Nurses' attitudes, compassion satisfaction and compassion fatigue associated with the pain management of patients with sickle cell disease in Saudi Arabia: A qualitative descriptive study**' was reviewed and was approved. Please note that this approval is from the research ethics perspective only. You will still need to get permission from the head of department or unit in KFMC or an external institution to commence data collection.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

If you have any further questions feel free to contact me.

Sincerely yours,



**Prof. Omar H. Kasule**  
Chairman Institutional Review Board--IRB.  
King Fahad Medical City, Riyadh, KSA.  
Tel: + 966 1 288 9999 Ext. 26913  
E-mail: okasule@kfmc.med.sa

King Fahad Medical City

IRB Approved  
28 APR 2015

## Appendix 6 Ethical Approval from the Hospital

الرقم  
التاريخ 1436 / 8 / 22 هـ  
المرفقات

المديرية العامة للشؤون الصحية بالمنطقة الشرقية  
General Directorate of Health Affairs  
لجنة أخلاقيات البحث العلمي  
1421 ت 8361000.



من	رئيس قسم الدراسات العليا والتدريب والتعليم الطبي المستمر
إلى	سعادة/ مدير الخدمات الطبية المحترم
صورة إلى	رئيس قسم التمريض/ رئيس قسم الطوارئ/ رئيس قسم العناية المركزة
الموضوع	طلب تمكين باحث لعمل دراسة

السلام عليكم ورحمة الله وبركاته

سعودي

طالبة دكتوراة  
جامعة موتاش - استراليا

د. هراء مكي الشيخ

نفيدكم بأنه تم مناقشة طلب المنكورة أعلاه بإجراء دراسة تحت عنوان:

**Nurses' attitudes, compassion satisfaction and compassion fatigue associated with the pain management of patients with sickle cell disease in Saudi Arabia: A qualitative descriptive study**

والموافقة عليه من قبل لجنة أخلاقيات البحث العلمي لدينا بالمستشفى.

نأمل تمكين المنكورة أعلاه من إجراء البحث وتزويدها بالمعلومات المطلوبة ما أمكن على ألا يتأثر سير العمل لديكم.

ونكم جزيل الشكر،،،،،



## **Appendix 7 Participants' Information Sheet**

### **Project:**

Nurses' attitudes, compassion satisfaction and compassion fatigue associated with the pain management of patients with a sickle cell disease crisis in Saudi Arabia: A qualitative descriptive study.

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

### **What does the research involve?**

The study involves a single face-face interview that is likely to take 60-90 minutes. The aims of the study are to: 1) explore and describe registered IBDC, ED and ICU nurses' attitudes and experiences in the pain management of patients with a sickle cell disease (SCD) crisis; and 2) measure and discuss their compassion satisfaction, compassion fatigue, and burnout associated with these experiences.

The interview will consist of three parts. The first part will involve sharing some of your history in working in IBDC, ED or ICU, demographic data in relation to education level and professional experience, and past experiences of caring for patients' with a SCD crisis. The second part will discuss your experiences, care strategies, and personal coping strategies when working in ED or ICU and looking after patients who have pain related to SCD crises. The third part of the interview will involve answering open-ended questions about how you deal with compassion satisfaction, compassion fatigue and/or burnout while caring for these patients. This part of the interview will also involve completing self-assessment of the extent to which you currently experience compassion satisfaction, compassion fatigue and/or burnout by answering some questions posed by the Professional Quality of Life (version 5) scale.

### **Why were you chosen for this research?**

As a Master of Nursing student undertaking research I am interested in identifying nurses' attitudes and experiences in caring for patients with pain associated with SCD crises. I am inviting registered nurses working in IBDC, ED and ICU with at least 18 months of professional experience to participate. IBDC, ED and ICU are the three critical areas for the care of these

patients, ED and IBDC are where patients are first assessed and treated, and the ICU is where the patients with severe complications including pain are admitted. Therefore you, as IBDC, ED or ICU nurses, have been invited to join the study to help us identifying nurses' attitudes, compassion satisfaction and compassion fatigue while caring for patients with pain associated with a SCD crisis.

### **Consenting to participate in the project and withdrawing from the research**

The purpose of the study will be advertised and explained in the IBDC, ED and ICU worksites. Nurses who are interested in the study will make direct contact with the researcher. Information about the project will be provided and written consent will be sought prior to interview participation. Interviews will be held in a private setting in the hospital.

Your participation is optional and you are free to withdraw from the study at any stage without any consequences.

### **Possible benefits and risks to participants**

It is likely that the nurses participating in this project will gain benefits from talking about and sharing their experiences of caring for people with pain secondary to SCD. During the interview the participants will also answer some questions related to quality of life (professional compassion satisfaction, compassion fatigue etc.) and identify their personal scores using these psycho-social metric scales. The findings from this will enable the participating nurses to identify their own extent of compassion satisfaction, compassion fatigue and burnout in relation to work environment. All of this should aid insight into care, which in the longer term will have implications for the quality of care for patients with pain related to SCD crises in IBDCs, EDs and ICUs. For some participants being part of such a research may be an important basis to inform their care for their patients. Talking about this may evoke some emotional reactions.

### **Confidentiality**

Participants will be given pseudonyms and de-identified for the purpose of interview transcription, and data recording. A study report will be submitted for publication, and papers will be presented at professional conferences and seminars. Pseudonyms will be used and every care will be taken to avoid identifiability of the participants.

### **Storage of data**

All interviews will be transcribed and saved on the investigator's private computer and the data will be password protected. After completion the project, data will be stored on a CD disk and it will be stored in a locked filing cabinet in a locked office of the School of Nursing and will be accessed by research team members as identified in the application form. According to Monash University policy, data will be stored for five years, after which time the principal researcher will discard the material.

### **Results**

The results will be available at the end of 2015, when a thesis about the research will be submitted to the university. Results will be submitted to journal articles after being completed and approved. Participants can contact the researcher by email for information in relation to the outcomes of the study.

### **For further questions you can contact**

Zahra Makki Ibn Alshaikh,  
Master of Nursing student

[REDACTED]

[REDACTED]

## Appendix 8 Participants' Consent Form

### Consent Form - Adult providing own consent

**Title** Nurses' attitudes, compassion satisfaction and compassion fatigue associated with the painmanagement of patients with sickle cell disease crisis in Saudi Arabia: a qualitative descriptive study.

**Protocol Number** CF15\111- 2015000054.

**Principal Investigator** Associate Professor Cheryle Moss

**Associate Investigator(s)** Associate Professor Jennifer Newton, Ms. Zahra Ibnalshaikh.

**Location (** [REDACTED] [REDACTED]

#### Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future career.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) \_\_\_\_\_  
Signature \_\_\_\_\_ Date \_\_\_\_\_

#### Declaration by Researcher<sup>†</sup>

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher<sup>†</sup>(please print) \_\_\_\_\_  
Signature \_\_\_\_\_ Date \_\_\_\_\_

<sup>†</sup> An appropriately qualified member of the research team must provide the explanation of P, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

## Appendix 9 Semi-Structured Interview Guide for Data Collection



**Nurses' attitudes, compassion satisfaction and compassion fatigue associated with the pain management of patients with a sickle cell disease crisis in Saudi Arabia: A qualitative descriptive study.**

Face-to-face interview with registered nurses working in ED, IBCU or ICU: Example questions.

<b>Question Context</b>	<p><b>Questions</b></p> <p>The following open-ended primary questions provide some structure to the various sections of the interview. Each primary question will be followed up by secondary/tertiary questions through the use of prompts and probes. There are three parts to the interview, part one should take 15-20 minutes, parts two should take 25-30 minutes, and part three should take 30-40 minutes.</p>
<p><b>First part:</b> Sharing some of your history in working in ED, IBCU or ICU, demographic data in relation to education level and professional experience, and past experiences of caring for patients' with a SCD crisis.</p>	
<b>Primary Questions</b>	<p><b>Introduction</b></p> <p><b>Primary 1-</b> I am interested to learn from you about your motivation for participating in this research. Can you tell me a little about this?</p> <p><b>Primary 2-</b> You currently work in ED/IBDC/ICU. Can you tell me a little bit about how long you have been working in this area of practice and at this hospital?</p> <p><b>Primary 3-</b> Before we go much further, can you tell me a little about your history as a nurse?</p> <p><b>Primary 4-</b>As you know a key part of this research is about caring for patients with a sickle cell crisis – can you tell me a little about your experiences with this? For example, How many patients have you cared for with this condition?; and How often do you see/care for patients with this condition?</p> <p><b>Primary 5 –</b> If you could rate your expertise as a nurse in caring for people with a sickle cell crisis in your workplace setting what would it be – expert, competent, or advanced beginner? Tell me about why you would rate yourself at this level?</p>
<p><b>Second part:</b> Discussing your experiences, care strategies, and personal coping strategies when working in ED, IBCU or ICU and looking after patients who have pain related to SCD crises.</p>	
<b>Primary Questions</b>	<p><b>Introduction</b></p> <p><b>Primary 1-</b> I am interested to learn from you about your strategies for caring for patients who have pain related to SCD crises. Can you tell me a little about this? – e.g. What do you do?; What do you try to achieve?;How do you manage the situation professionally?</p> <p><b>Primary 2 –</b> I just have little more to ask you about this- How do you care for these patients during painful crises? Do you face any practical challenges while delivering this care? Is there a pain management protocol to follow?</p> <p><b>Primary 3-</b> Can you tell me a little bit about what is satisfying in the care of patients who have pain in this situation? It would be great if you could give me an example of this.</p> <p><b>Primary 4-</b> Can you tell me a little bit about what is challenging or stressful in the care of patients who have pain in this situation? It would be great if you could give me an example of this.</p> <p><b>Primary 5–</b>Who was the last patient that you saw, treated or cared for with a SCD crisis and who had pain? Can you provide me with a summary of that patient's scenario... I am particularly interested in:</p> <p>5.1 What was the patient's crisis journey?</p> <p>5.2 What you and the team did to manage the situation?</p> <p>5.3 How the care situation affected you as a person and as a professional – eg did it make you sad, happy, satisfied, dissatisfied, stressed or relieved, tired or energated</p>

	<p>etc?</p> <p><b>Primary 6</b> – Is there anything else you would like to say about your experiences, care strategies, and personal coping strategies when working in ED, IBDC or ICU and looking after patients who have pain related to SCD crises?</p>
<p><b>Third part:</b> Answering open-ended questions about how you deal with compassion satisfaction, compassion fatigue and/or burnout while caring for or looking after patients who have pain related to SCD crises.</p>	
<p>Primary Questions</p>	<p><b>Introduction</b> – We have two activities as part of this section of the interview. Firstly – I would like you to complete a self-assessment of your own degree of compassion satisfaction, compassion fatigue and/or professional burnout. Then I would like to talk with you generally about these in relation to your current situation and in relation to caring for people in ED, IBDC or in ICU with who have pain related to SCD crises.</p> <p><b>Primary 1-</b> The following survey will take about 10-15 minutes of your time – it is called a professional quality of life scale... these are 30 questions to answer and then we can score your results together. The self-assessment is undertaken at this point.</p> <p><b>Primary 2-</b> Having undertaken the self-assessment what do you think about the results? Are there any surprises for you? Do you think the assessment is accurate?</p> <p><b>Primary 3-</b> Beyond the findings from the scale and the self-assessment - What do you generally think about:</p> <p>3.1 your degree of compassion satisfaction? (please provide an example)</p> <p>3.2 your degree of compassion fatigue? (please provide an example)</p> <p>3.3 your degree of burnout? (please provide an example)</p> <p>3.4 As a person and a professional in relation to these three experiences or professional states - how do you keep yourself healthy, satisfied or motivated at work?</p> <p><b>Primary 4-</b> I am particularly interested in relating these professional states to the care of ED, IBDC or ICU patients who have pain related to SCD crises. Can you now think of your answers and scores and the care of these patients. What do you generally think about:</p> <p>4.1 how caring for these patients affects your professional compassion satisfaction? (please provide an example)</p> <p>4.2 how caring for these patients affects your professional compassion fatigue? (please provide an example)</p> <p>4.3 how caring for these patients affects your professional burnout? (please provide an example)</p> <p>4.4 As a person and a professional in relation to these three experiences or professional states - how do you keep yourself healthy, satisfied or motivated while caring for these patients?</p> <p><b>Primary 5-</b> In an ideal and future world, what would help you to achieve more satisfaction and motivation when faced with caring for people in ED, IBDC or ICU with pain related to SCD crises?</p> <p><b>Primary 6-</b> Before we move towards the end of this interview is there anything else that you would like to add or to talk about?</p> <p>Summary &amp; closure &amp; where to from here</p>

## Appendix 10 Professional Quality of Life Version 5 Survey

### PROFESSIONAL QUALITY OF LIFE SCALE (PROQOL)

#### COMPASSION SATISFACTION AND COMPASSION FATIGUE (PROQOL) VERSION 5 (2009)

When you [help] people you have direct contact with their lives. As you may have found, your compassion for those you [help] can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a [helper]. Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the *last 30 days*.

	1=Never	2=Rarely	3=Sometimes	4=Often	5=Very Often
_____ 1.					
_____ 2.					
_____ 3.					
_____ 4.					
_____ 5.					
_____ 6.					
_____ 7.					
_____ 8.					
_____ 9.					
_____ 10.					
_____ 11.					
_____ 12.					
_____ 13.					
_____ 14.					
_____ 15.					
_____ 16.					
_____ 17.					
_____ 18.					
_____ 19.					
_____ 20.					
_____ 21.					
_____ 22.					
_____ 23.					
_____ 24.					
_____ 25.					
_____ 26.					
_____ 27.					
_____ 28.					
_____ 29.					
_____ 30.					

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## YOUR SCORES ON THE PROQOL: PROFESSIONAL QUALITY OF LIFE SCREENING

Based on your responses, place your personal scores below. If you have any concerns, you should discuss them with a physical or mental health care professional.

---

### Compassion Satisfaction \_\_\_\_\_

Compassion satisfaction is about the pleasure you derive from being able to do your work well. For example, you may feel like it is a pleasure to help others through your work. You may feel positively about your colleagues or your ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction related to your ability to be an effective caregiver in your job.

The average score is 50 (SD 10; alpha scale reliability .88). About 25% of people score higher than 57 and about 25% of people score below 43. If you are in the higher range, you probably derive a good deal of professional satisfaction from your position. If your scores are below 40, you may either find problems with your job, or there may be some other reason—for example, you might derive your satisfaction from activities other than your job.

---

### Burnout \_\_\_\_\_

Most people have an intuitive idea of what burnout is. From the research perspective, burnout is one of the elements of Compassion Fatigue (CF). It is associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that your efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that you are at higher risk for burnout.

The average score on the burnout scale is 50 (SD 10; alpha scale reliability .75). About 25% of people score above 57 and about 25% of people score below 43. If your score is below 43, this probably reflects positive feelings about your ability to be effective in your work. If you score above 57 you may wish to think about what at work makes you feel like you are not effective in your position. Your score may reflect your mood; perhaps you were having a “bad day” or are in need of some time off. If the high score persists or if it is reflective of other worries, it may be a cause for concern.

---

### Secondary Traumatic Stress \_\_\_\_\_

The second component of Compassion Fatigue (CF) is secondary traumatic stress (STS). It is about your work related, secondary exposure to extremely or traumatically stressful events. Developing problems due to exposure to other's trauma is somewhat rare but does happen to many people who care for those who have experienced extremely or traumatically stressful events. For example, you may repeatedly hear stories about the traumatic things that happen to other people, commonly called Vicarious Traumatization. If your work puts you directly in the path of danger, for example, field work in a war or area of civil violence, this is not secondary exposure; your exposure is primary. However, if you are exposed to others' traumatic events as a result of your work, for example, as a therapist or an emergency worker, this is secondary exposure. The symptoms of STS are usually rapid in onset and associated with a particular event. They may include being afraid, having difficulty sleeping, having images of the upsetting event pop into your mind, or avoiding things that remind you of the event.

The average score on this scale is 50 (SD 10; alpha scale reliability .81). About 25% of people score below 43 and about 25% of people score above 57. If your score is above 57, you may want to take some time to think about what at work may be frightening to you or if there is some other reason for the elevated score. While higher scores do not mean that you do have a problem, they are an indication that you may want to examine how you feel about your work and your work environment. You may wish to discuss this with your supervisor, a colleague, or a health care professional.

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2

**WHAT IS MY SCORE AND WHAT DOES IT MEAN?**

In this section, you will score your test so you understand the interpretation for you. To find your score on **each section**, total the questions listed on the left and then find your score in the table on the right of the section.

**Compassion Satisfaction Scale**

Copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

- 3. \_\_\_\_\_
- 6. \_\_\_\_\_
- 12. \_\_\_\_\_
- 16. \_\_\_\_\_
- 18. \_\_\_\_\_
- 20. \_\_\_\_\_
- 22. \_\_\_\_\_
- 24. \_\_\_\_\_
- 27. \_\_\_\_\_
- 30. \_\_\_\_\_

**Total:** \_\_\_\_\_

The sum of my Compassion Satisfaction questions is	So My Score Equals	And my Compassion Satisfaction level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

**Burnout Scale**

On the burnout scale you will need to take an extra step. Starred items are "reverse scored." If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way though they can tell us more about their negative form. For example, question 1. "I am happy" tells us more about

- \*1. \_\_\_\_\_ = \_\_\_\_\_
- \*4. \_\_\_\_\_ = \_\_\_\_\_
- 8. \_\_\_\_\_
- 10. \_\_\_\_\_
- \*15. \_\_\_\_\_ = \_\_\_\_\_
- \*17. \_\_\_\_\_ = \_\_\_\_\_
- 19. \_\_\_\_\_
- 21. \_\_\_\_\_
- 26. \_\_\_\_\_
- \*29. \_\_\_\_\_ = \_\_\_\_\_

**Total:** \_\_\_\_\_

The sum of my Burnout Questions is	So my score equals	And my Burnout level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

You Wrote	Change to
	5
2	4
3	3
4	2
5	1

the effects of helping when you are *not* happy so you reverse the score

**Secondary Traumatic Stress Scale**

Just like you did on Compassion Satisfaction, copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

- 2. \_\_\_\_\_
- 5. \_\_\_\_\_
- 7. \_\_\_\_\_
- 9. \_\_\_\_\_
- 11. \_\_\_\_\_
- 13. \_\_\_\_\_
- 14. \_\_\_\_\_
- 23. \_\_\_\_\_
- 25. \_\_\_\_\_
- 28. \_\_\_\_\_

**Total:** \_\_\_\_\_

The sum of my Secondary Trauma questions is	So My Score Equals	And my Secondary Traumatic Stress level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

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